

## TOM AND JACKIE'S STORY

Mom and dad could start our story right at the time our home was raided, but that would only tell the reader half the story...

Our son was born on March 31, 1986, eight years before Asperger's Syndrome was included in the Diagnostic and Statistical Manual of Mental Disorders. Bearing this in mind, the beginning of our son's story is also the story of our family, a school system, and the medical and psychological professionals struggling to help our son's deficits. As a child, our son would frequently become overstimulated due to the amount of people and noise associated with the large family gatherings. In response to this overstimulation, our son would often cower in a corner of the room in a fetal position. Overtime, he slowly began to learn how to engage with some of his family members—a significant development which occurred only after years of loving support and positive reinforcement.

Our son is the eldest of three children. He was colicky, cried often, and digestive issues frequently resulted in episodes of projectile vomiting. He did not tolerate efforts to physically console him. As such, it took a tremendous amount of time and effort to calm him. The slightest noise or unexpected physical contact would upset him. As soon as he could crawl and eventually walk, our son was noticeably overactive and constantly on the move. We struggled to slow our son down and refocus his attention on meeting his basic needs such as eating and using the bathroom. He did not respond well to verbal cues as if he did not understand. For a time, we believed he was deaf. His hearing was tested and results were normal. He often used gestures or pointing instead of words to try to communicate his needs. Emotional meltdowns invariably occurred if we did not understand his awkward gestures. Communication with our son was a slow and tedious process as he seemed more interested in running than learning how to talk. It was difficult for our son to sit still for a period of time and maintain eye contact.

Our son was in daycare two days a week while mom worked. Caregivers at the daycare center noted that he had separation anxiety when mom dropped him off in the morning. They also noted that he displayed a strong attachment and fixation to certain toys so much so that he had trouble letting go of them to even eat or rest. Members of the daycare center also noticed he had trouble going out in public, which largely stemmed from his inability to sit still and quiet for a long period of time and his inability to interact with people in public.

Though our son participated in play groups with neighborhood children, he lacked the social savviness to fit in with his peers. This frustrated him and he soon began to display self-injurious behavior such as head banging as a coping mechanism. He began to withdraw into himself. Instead of interacting with others, he preferred to take his toys apart and examine how they were made. He seemed to feel better in his own world, free of awkward and uncomfortable social interactions. For our son, mere skin contact was excruciatingly painful. Toilet training was slow and he was virtually incontinent for a time, apparently because of his inability to stop what he was doing to go to the bathroom on time.

Our son was never able to sleep through the night. Mom would typically spend at least an hour each night playing soft music and reading books to provide a quiet and calming atmosphere, often to no avail.

## TOM AND JACKIE'S STORY

Preschool was the beginning of many social difficulties that our son was about to encounter throughout his life. The preschool teacher told us that our son seemed to be in his own world and had limited interactions with his peers in the program, preferring to play with certain toys instead. He also had trouble reading and writing.

In our son's early years, mom still worked as a prenatal nurse and labor coach at a center designed for pregnant adolescents. Mom eventually realized that our son's persistent social and academic struggles required her constant attention. She set aside her career for the next sixteen years while she cared for our son and helped him navigate a world that seemed unforgiving to his developmental disabilities.

In the fourth grade our son's education plan was reevaluated. Through a new test that was performed by the evaluator due to a gut feeling she had, our son was tested for mathematical matrices which is the ability to sequence numbers. He scored at the college level matrices and was found to be in the superior range of nonverbal intelligence. His evaluator commented that "Your son's brain is wired and operates like a computer." However, he was also shown to have a 19 point spread between verbal and nonverbal reasoning/visualization.

Each new school year brought with it ever more increasing stresses for our son and concerns for us and what we can do for him. This culminated in our son's fifth grade year.

By the start of the second half of the school year, the teacher noted that our son often sat and stared, ignoring directions. Mom finally decided it would be in our son's best interest to pull him out of public school and homeschool him. Mom and dad had a neighbor who had her children in a home-school network and spoke highly of it. Mom decided to observe our son in the classroom, which confirmed her belief that it was time to take him out of class. Dad was not convinced and very hesitant about making a huge change in our son's life. Dad also went to observe his son in the classroom for himself. He saw our son staring into space with a running nose, apparently unaware of anything going on around him. Dad came home and did not hesitate to tell mom that she was right. We took our son out of school shortly thereafter.

Around the middle of 1997 our son was diagnosed at the age of eleven with Asperger's Syndrome. Just three years after the diagnosis first appeared in the Diagnostic and Statistical Manual. He had had many different diagnoses before that one as various professionals struggled to explain his odd presentation of symptoms. For our son to have been diagnosed with Asperger's Disorder so early on in the history of its clinical usage certainly demonstrates that his case was an obvious one to someone who was aware of the relatively new diagnosis.

## TOM AND JACKIE'S STORY

In the year 2000 we prepared to have our son reenter public school. We appealed to our state's protection and advocacy services for students with mental disabilities. Together we prepared to have our son's reentry by teaming with a very dedicated advocate from this advocacy service and our son's developmental disability case manager. We eventually had seven pre enrollment IEP meetings totaling 14 hours with education counselors, special education teachers, principals and vice principals, and education case managers, as well as mainstream educators.

There is so much more that we could state about raising someone on the spectrum... so many confusing, frustrating looks from family, friends, and teachers. Lost friendships...our son's, and our own friendships. Why? Because our son didn't "fit in". This was for us indirect and direct systematic rejection over many years. We slowly got used to this rejection, we learned to live with it. We were for the most part respected in our community. Even complimented for our parenting efforts raising someone on the spectrum. However, when we ran into neighbors, "old" friends, we engaged in small talk, nothing more than that...we knew better then to try and forge more "meaningful" relationships. Many meaningful friendships with other parents are forged as a result of their children's friendships with their peers.

We are presenting to you all of our son's early childhood development as a way to introduce to the reader the lifelong struggles for those on the spectrum, and their parents struggles raising someone on the spectrum.

Fast forward to 2012. So many countless sacrifices were made up to this point. And they all seemed to have been worth it...our son had graduated with an associate's degree 6 years earlier from a local technical college. He struggled with full time employment for that 6 year period but, just recently landed a full time position in his field. Every Tuesday mom and dad attend Eucharistic Adoration of the Blessed Sacrament, (a Catholic service). We were on our knees giving thanks for all the progress our son was making. We left the service at 6pm. Just two hours later we were all in handcuffs.

We were in our family room watching TV when we heard a loud bang on our door. Our, at the time, 16 year old daughter answered the door. Men with helmets dressed in camouflage and black boots, bulletproof vest, brandishing assault rifles and glock pistols rushed in. Outside, neighbors watched in horror as four men ran to the four corners of our lot.

**AS IF WE WERE THE MOST FEARED, MOST DANGEROUS FAMILY IN THE NATION.**

Our son was arrested for possession of child pornography. He was taken into custody charged and inexplicably released the night of the raid, totally free with no restrictions of any kind...for three and a half years! So why the expensive, military raid on our home?

## TOM AND JACKIE'S STORY

Our daughter was traumatized due to the raid on our home. She began to miss school a lot. Her grades started to fall. We sought counseling for her. Shortly thereafter, with mom at her side our daughter revealed to her counselor the raid on our home. It turns out that the counselor works for a counseling service that also operates a state accredited counseling service for sex offenders. We suggested to our son that maybe he should consider attending a service like this. Our son decided to try it out. He eventually committed to 146 sessions over a three year period. Towards the end of his sex offender treatment he was finally arraigned, eventually pleading guilty to possession. His prosecutors agreed with our son's defense attorney to three years probation. No incarceration.

Our son's judge could have cared less about this plea agreement, or all of what our son has struggled through his whole life, or his very well documented disabilities, or the rare occurrence of an offender receiving sex offender treatment BEFORE he is even arraigned, and lastly...most importantly, the pretrial psychological report administered by a forensic psychologist that determined that even though our son is 28 years old, he has the social adaptive skills of a 6 year old! He sentenced our son to 3 years incarceration.

In the final analysis, our son is not a criminal. He does not possess a criminal mind. He simply is a person who was born with a developmental disability that created for him great difficulty in understanding the nuances, the gray areas of boy/girl socializing. He wanted so much to be a part of this world but was not born with the ability to participate in it as neurotypicals can. So, he turned to a world he did understand. The cyber world. What his vulnerable mind didn't know is that even though this illicit material is:

- free,
- just a few clicks away,
- always available 24/7/365,
- in the privacy of one's home,
- no overt warnings of any kind,

If you *look at* illicit images on a computer our criminal justice system can turn your life into a nightmare...a lifetime nightmare.

Our developmentally disabled son is now in prison. What is it like to have a DD person incarcerated?

Here is just one of many emails from our son on what he is challenged with daily in prison:

6/18/2018 12:38:41 PM

*Yesterday was a rather bad day, Joe has been bullying me a bit, slapping me on the belly and asking stupid questions and at lunch he was pulling and shoving me and when I asked Eric where Stewie was apparently I was interrupting him while he was talking to this annoying guy and that guy followed me to the ice machine to ask what my problem was. It was all rather aggravating! I guess there will always be bullies around here.*

## TOM AND JACKIE'S STORY

For someone with a developmental disability prison is the very worst environment to be placed in. You are surrounded by inmates all the time. You cannot get away from them. There is no private time. It is a very *unnatural* social environment. An inmate must use his “wits” to survive in a place like this. An inmate must *socially adapt*, and quickly...