



Getting the Diagnosis

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Recently I was asked by TxP2P to tell my story of motherhood. Initially I felt confusion about how to tell a story that has gotten nothing but longer and more complex over time and wondered what to focus on. Well, I will start at the beginning, I guess, and jump around as needed to describe the long and winding road we've been on.

Spoiler alert **I'm still here, still standing, and I didn't forget how to smile or laugh.

My beloved, highly anticipated son was the answer to countless prayers when he arrived in 1999 after a full term and healthy pregnancy. He is such a miracle and I remember that always, since a full term gestation had been so elusive before. Upon arrival he was absolutely perfect! We could hardly believe our shiny good fortune and it erased all of the pain of longing that came before. His APGAR score was 9! The nurses joked that scores of 9 and 10 are generally reserved for the children of doctors, further reassuring us of how perfectly born he was. I immersed myself in glorious mommy-hood, complete with all manner of mommy and me classes, play dates and homemade baby food.

Incredibly this little baby boy had an astounding ability to "introduce" me to strangers, who became new friends, without saying a word. He used the methods that only babies can communicate so well-- 1) infectious laughter, 2) love of play and outdoor activity, and 3) a sweet face framed in gorgeous curls. His perfection attracted admiration and invitations from the world. Assured of a bright, bright future we accepted my son's precocious development as just another feature of the enormous gift we were granted. He began walking at an early age and spoke right on schedule and with lovely pronunciation to boot. Little did we know that this state of bliss would last only a little more than 2 years nor that some features of this precocious development signaled emerging developmental disability. Even when I became concerned enough to seek my pediatrician's input, never ever did I imagine that it would permanently impact this perfectly limitless potential.

And then it started....or maybe more accurately, it accelerated so much so that I could not wait for the pediatric neurology appointment we had to schedule three months in advance for the first available appointment time. "It" would later be named by professionals and DSM codes but "IT" was the fact that he'd become routinely agitated during Music Together classes that he formerly enjoyed intensely and without tantrum. "IT" was that I could not leave the children's museum, especially the toy train tables, without a complete meltdown. "IT" was the fact that visitors could not leave my home without prompting tearful goodbyes from my son nor could we attend a play date like I'd become accustomed to. He was so nervous arriving as we drove up and it became unrealistic to expect him to play with the others while I drank coffee and socialized with my peers as had been routine up until then. Countless times before, he had played and played well without direction from any adult. Maybe most impressively

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"IT" was his verbatim dramatic recital of stories that we introduced to him from the books that became such good companions to him that he slept with them instead of soft toys. Since my husband is a literacy expert, we devoted ourselves to literacy readiness and read volumes to our son regularly. He so enjoyed our reading to him. (We did too)! He often chose books for us to read and even screamed when they were finished, pleading for a repeat. At bedtime, if we refused to read another story because it was time for sleep, we'd hear his completely accurate rendition as he comforted himself to sleep. Never did I assume this would be considered a profile of autistic spectrum disability, but in retrospect it was a part of what was raising my internal alarm. And most of all my son was talking too much. I know that sounds crazy but that was the thing that got my full attention. Too much talking. It was constant. And I mean constant. He woke up and this stream of consciousness would start. And we knew some of the words before they emerged from his mouth, because they were read to him at nap and bedtimes from those books he loved (and still loves) so much.

Voicing my concern met with complete dismissal by everyone I knew, including some persons with advanced degrees that reassured me that kids are weird and that mine seemed no weirder than others. There were books at the time that made this case and they became bedtime comforts to me. I felt reassured, but then the manifestations began to mount and multiply even as others around us continued to sooth my fears. And he even stopped sleeping. So at 2 yrs and 6 months old we finally got our visit with a neurologist. Within about 20 minutes he was diagnosed with something called PDD-NOS. Seeking to quickly clarify as I struggled to keep my son content during the neurology appointment, I promptly asked, "Does that have anything to do with autism?" The doctor responded "No," and I was very relieved. It occurred to me to ask this question because in the face of all of the reassurance from friends and family, I'd taken to joking about being dismissed, "Not to worry; that's just the Autism kicking in." And in the interim as I waited for the neurology appointment, I'd hit the Internet Explorer. This was a long time ago in terms of the internet, but I was an early adopter when it came to accessing medical information online. I'd run into something called "childhood disintegrative disorder" and coincidentally one of my friends did too and we wondered if that was what was happening to James.....it escapes me now why that label seemed accurate but nonetheless when the neurologist said "No" to the question of autism I was so relieved. Then astonishingly my son was referred to a speech language pathologist that day. I was surprised because he spoke so very well that I never in a million years would have thought that remedy would include speech therapy. I was prepared instead for the possibility of some sort of psychological disorder that could be remedied with a little play therapy.

Well, as I said, I was an early adopter on medical searches online, so as soon as I got home I cranked up the old PC and when I typed in "PDD-NOS" and searched, all links led to "Autism." I was furious! And frightened! Confused! Confounded and very, very worried. It was nearly 4pm when we'd gotten home from that life changing appointment and that meant I might have an opportunity to get that doc on the phone and demand....clarify.....why hadn't the question of autism been answered with an acknowledgment? This would prove to be my first lesson about how meaningless the words and labels are to name amorphous conditions that defy explanation. I picked up the phone and got no one,

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despite persistence and resourceful phone tree maneuvering. I spent that night, as I would many times over, contemplating the unknowable future.



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