

Our Journey

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It seems like only yesterday but in fact it was 19 years ago that we welcomed our third child and beautiful son Matthew into the world and excitedly took him home to meet his two older sisters. My husband and I felt pretty confident that our third child would be an absolute piece of cake and why would we think otherwise. We had already raised two wonderful little girls and how different could raising this charming little boy be.

Matthew was a pretty typical baby at first. Naturally he was adored by his older sisters and was showered with more attention and love than you could imagine. When I look back on those early days and ask myself what early signs we may have had that something was amiss a few come to mind.

At the time we just attributed some of these to the fact that he was our first “boy” and everyone kept telling us that boys are just different. The first red flag came within a few months of his birth. I was breastfeeding yet I had a terribly constipated baby. Weekly visits to our family doctor didn’t tell me why he was suffering in this way but only given another recommended over the counter remedy to try. This problem never got better and we were never given the help to discover why he was having this problem and what to do to prevent it from continuing.

I can remember the nightly episodes of “mommy magic” when after his bath I would begin to swaddle him in his blanket and he would almost immediately begin to stop fussing and be completely asleep by the time I had tucked in the last tiny corner . It was like I was casting a magic spell over him and at the time we thought the whole thing was quite entertaining for all of us to witness. As he got older and too big to swaddle he would lay under the cushions on our couch and fall asleep. We thought this was both amusing but just a bit odd. Boys really are different we would hear ourselves say with more frequency. .

The next event that I remember and documented came after his 4 month immunization. I held a screaming baby for 3 days after that episode and felt a mother’s intuition that “he didn’t handle that very well”. When I returned to the health clinic as expected on his next visit and passed on my concerns to the health nurse who didn’t take them seriously and pretty much ignored me I let her do what she thought best and uncomfortably let her immunize him again. While I know there have been many studies that say they proven there is no link between autism and vaccinations none of those studies have proven to me that they did not compromise my son’s health and until then we are still suspicious about that. That is all I will say to that.

In other ways Matthew seemed to be developing as expected. He did start speaking words as expected and was soon labelling everything. One of the first words Matthew spoke was “again”. He let us know at an early age he had an affinity for Thomas The Tank Engine stories. After finishing one story he would happily request another ...”again “. At the time I thought his need for repetition only meant how much he enjoyed the story. Needless to say I think we could still recite every volume of Thomas The Tank Engine ever written 19 years later.

Then his words were becoming fewer and he eventually replaced them with interesting and complicated “air finger drawings” and would repeat simple questions rather than answer them. It was at that point when my husband and I realized there might be something wrong. I nervously approached our family doctor with our concerns and she started the process of getting a referral to the Glenrose Preschool Assessment clinic. We were told the wait to get in could take at least 10 months. While 10 months seemed like forever to wait we reassured ourselves that if indeed something was wrong there would be a treatment or program or something to help us if we needed it when the time came. We decided to enrol our son in our neighbourhood playschool while we waited for our appointment at the Glenrose.

On the first day of play school I communicated to the teacher that we had some concerns about our son and that she should feel comfortable being as frank as she wanted where our son was concerned because when we finally did get in to the Glenrose we wanted to provide them with as much information as we could about him.

In the beginning I often stayed at the playschool to help facilitate some kind of play between Matthew and the other children. I only left him on his own the odd time when I just needed a sanity break. It was on those rare occasions that the playschool teacher would tell me “Matthew answered questions at story time today” or “he is just fine Jean you shouldn’t worry”. At the beginning I started to doubt my suspicions just a bit that there was something indeed wrong until it quickly became evident that I had to worry more about this “teacher” than I did about my child. She made extremely unprofessional comments about the other children that really made me wonder what was going on when I wasn’t around. It didn’t take long for me to learn from other parents that she was communicating to the other children and to them that my son was really weird and their children shouldn’t play with mine.

My son never returned to that playschool after that and although it was difficult for me to help facilitate the immediate removal of this person I just knew that she should not have been working anywhere near my child or anyone else’s for that matter.

When Matthew was around 4 years of age our much anticipated visit to the Glenrose finally came and after our two days of testing and observations were completed we were given the information that while it looked like a formal diagnosis of autism was suspected he would receive a diagnosis of Pervasive Developmental Disorder for the time being. The only help and advice we were provided with when we left the Glenrose was the recommendation that it would be beneficial for our son to be around other children his own age and to seek out private speech therapy. We were handed a few brochures to look at as we would have to consider an early education site for the fall.

I remember going home feeling so very disappointed that there was no direct help, no special program and not much support for us at all. It was sad thinking that my son was the one who would never be invited to birthday parties, never make or have friends, and as far as excelling in sports like his father or having the same kind of academic potential I wasn’t even sure he would learn to speak. What about his future as an adult. How would he manage? Would he be able to get a job? Who would look after him when we were gone? It was all pretty overwhelming.

We came to the conclusion pretty fast that it was up to us to find as much help as we could in the months that followed. Right away we found an awesome private playschool in another part of the city and hired a private speech therapist to work with our son at home and at his playschool. This came with a hefty monthly bill and meant that our other children had to forgo their extra curricular activities so we could budget for all of this help we felt was so important. It was one of the most difficult things to tell our other older children. Matthew was the priority at that time and would be for a long time to come.

We started investigating all types of treatment options and through our search heard about something growing in popularity called Louvas. It sounded interesting but wasn't readily available here in Canada only in the United States. What was available here and sparked our interest was information that led us to believe that there may have been an environmental factor involved with our son's diagnosis. We were beginning to hear about more and more families that we knew of also receiving the same diagnosis for some of their children. We would joke about it being something in the water – but really we started to wonder if that were actually true. We were just parents who at that particular time were looking for answers and looking for something that would help our child. There wasn't much of either at the time. Like many parents we were practically willing to “sell the farm” to try just about any and all treatment options and anything else that might help our son.

While I won't go into much detail about what treatment options we did trial they were all alternative therapies. Before venturing into any one we would pass the information on to our contact at the Glenrose and ask for their opinion first. For the time we all agreed that most of the treatment options we considered were nothing more than “food for thought”. While none of the alternative therapies we tried gave us the outcomes we desired we also can't say they did not improve his condition and most importantly we have no regrets. We never felt we had to justify what we were trying to do for our son because we were his parents and isn't this what parents do. You do everything you can to help your child.

Before we knew it we had to pick a kindergarten program for Matthew. After much researching we chose the Heritage School for Matthew's kindergarten placement that fall. This was a private school at the time which offered what seemed to us a Cadillac service for our son. For a fee our son would have a full time speech therapist in the classroom working closely with a trained teacher and a curriculum that seemed to be the best fit for our needs. Unfortunately for us this was the same year in which the Heritage School moved under the umbrella of the Edmonton Public School board and early that fall we were told to look for a new placement for our son for the following year as the criteria for enrolment would be changing. We had chosen this school in the first place because we felt we had secured a long term placement. We were very disappointed to learn that we had to search for a new placement for the following year. This was also the year we knew we needed to confirm a formal diagnosis of autism for our son so we could begin looking at what our options could be for him for the following year. The consultant was recruited and he spent a few days observing Matthew in the classroom, interviewing us and administering some tests. The day he requested that I come in to meet with him to discuss his results was a day I will never forget. The consultant led me down the long corridors of the school (I remember thinking that we were so far away I would probably get lost finding my way back) until he chose an empty classroom as far away from the class as possible and invited

me to sit in one of the available seats. Before I was even seated in my chair he slammed Matthew's file down on the table and in a very angry accusatory tone asked me what this nonsense about alternative therapies was all about. I felt immediate anger. I very calmly informed him that he wasn't there today to discuss that. He was there to discuss his results and to look at making a formal diagnosis of autism for my son. I explained to him that if our conversation was going to continue in that direction I was leaving. He didn't like that response and when the next comment out of his mouth attacked me personally I left the room. We did eventually find and work with a different consultant who delivered what we had suspected all along, a formal diagnosis of autism.

For grade one we decided to enroll Matthew in a program for children with autism at Allendale school. While we were never really comfortable that we had made the right decision in that placement we were introduced to the one person who to this day has made the biggest impact on not just my son but on us as parents. Matthew's grade one teacher was a force to be reckoned with. His teacher that year was also new to the school and right away communicated to us that while she wasn't an expert in autism she did have a strong background in working with children who had behaviour concerns. She believed that every child could learn no matter how severe their behaviours and she was dedicated and absolutely driven in helping each of her students achieve as much as they could. She taught us a family to always set the bar high when it came to our son. Matthew accomplished more that year in her classroom than we ever imagined. In all of the years of schooling that followed we have never had a teacher that committed or driven to helping her students as she was and we are forever grateful.

For the remainder of Matthew's elementary schooling he attended our neighbourhood school which offered an Opportunity program. It was the right fit for us. Prior to making that decision we had visited numerous schools that offered various specialized programs and met with many school principals who either welcomed us with open arms or did everything they could to keep "a student with that problem" as far away from their school as possible.

It was right about this time that we were given the advice from someone at The Autism Society that we should think about contacting Handicapped Children's Services (now known as FSCD) to discuss acquiring some supports for our family. I had no idea this agency existed or what they could do for us. Once I fully understood what they could offer our family we drew up a contract to include hours for respite and work related childcare. It did not take us long to find the perfect staff person for our son. She provided community support and much needed respite when we needed it. She stayed with us for a very long time. In fact we have only had to hire two staff during the period we had a contract with Handicapped Children's Services and then Family Support for Children with Disabilities.

Our second staff person, Jason came to us through the Autism Society's Summer Program. We grew very fond of Jason and he really liked working our son, lived close to us and was available to take over full time when our first staff person moved out of country to continue her education. Jason was able to stay on with us for several years up until our son turned 18 and he transitioned to PDD. The transition to PDD and adult services began for us last year and we are still negotiating adequate funding and support for our son. The transitioning process has

been long. Matthew was told he is eligible for PDD funding but what we have been offered is far from adequate and so we are preparing for our next level of the appeal process. Matthew attended LY Cairns for his junior and senior high school years and is still attending . Part of the high school program includes several rounds of work experience. This was something I really struggled with in the beginning. Could Matthew cope with an unsupported work experience placement? Would he be safe?

While the school will help somewhat with finding a work experience placement for their students parents are encouraged to seek out and place their child with an employer. Matthew successfully participated in several rounds of group placements before we thought he was ready to go it alone. That was a huge step for us.

When Matthew was in grade 11 we approached our local Heritage Safeway store to consider taking Matthew on for his 3 week placement. I was thinking ahead and wanted to find something that was close to home so that he could walk to his placement.

Like most mothers I was desperate for my son just to be given an opportunity and I was preparing all kinds of "deals" I could offer them just to get his feet in the door like "I could do on the job coaching after I was done my job if they felt he needed that". As we made our way to the store that early Saturday morning I had thought of several other unrealistic deals by this time. Thank goodness as things turned out I didn't have to open my mouth and deliver any of them . I was more nervous that morning then I have ever been for any of my past job interviews!

We were introduced to the manager immediately and he took us into his office for an impromptu interview. As we took our seats I could see from the corner of my eye that Matthew was comfortably slouching rather than sitting straight in his chair and did I detect the beginning motions of a humungous yawn forming on my sons face... yes indeed it was...and it seemed to last forever! Apparently all that pre coaching practice the night before was completely forgotten.

To my great relief the manager didn't seem to be quite as mortified as I was at this as he went on to explain that he really didn't like just placing students for work experience because when they were done they usually didn't stick around. He would much rather consider giving Matthew the opportunity of accommodating his work experience placement with the condition that if he did a good job they would offer him the opportunity of being part of their team.

I was completely stunned. I had gone in thinking we had a slim to none chance of finding a work experience placement but it never entered my mind we would be considering the offer of a part time job. We gladly accepted his generous offer!

The manager told me he knew a bit about Matthew already as Jason our respite provider also just happened to be employed at his store and he took occasion to share his many adventures with our son with hm. When Matthew successfully finished his work experience placement and the manager asked Jason for his opinion on how he thought Matthew would do in his store we were over the moon excited when he called us in to discuss the offer of a part time job with them. That was over a year ago.

Matthew is still employed with Heritage Safeway and we have noticed this sense of community that is developing around him. His coworkers are very supportive and seem to appreciate his presence when they are working with him. They tell me what a good job he is doing. Our neighbours have noticed that he is employed there and tell us too what a great job he is doing. The manager has reassured me that if any concerns need to be dealt with he would call us first.



Safeway Customer Service Manager Maxine Reid, Matthew Ashmore and Heritage Safeway Manager Phil Hanevich

What is remarkable to me about this part of our journey is the fact that the offer of employment happened when we least expected it. Matthew wasn't asked to change who he was in order to be accepted. They accepted him just as he is and gave him the chance to prove that he could be successful in being a viable and important member of the Safeway team. We are so proud of Matthew and grateful to the staff that work along with him and support him.

At the age of 19 Matthew has acquired a good functional base of language. He still has difficulty expressing himself and understanding specific directions at times. He asks what specific words or phrases mean all the time. Abstract words he doesn't quite understand

like "motivation" or "will power" have to be explained visually with a picture (if I can find one suitable) or in the simplest way possible. He doesn't draw pictures in the air with his finger anymore but draws incredible detailed pictures of his favourite subject matter; Super Heroes and Walt Disney characters. While he didn't get invited to lots of birthday parties he did get invited to some. (We discovered pretty fast that that bothered his parents more than it did him.) He does not have friends that visit him socially on a regular basis but that doesn't mean we can't find opportunities for him to participate in social activities. Most importantly he is happy and we are very lucky to have him in our lives. He has taught us what is truly important.

Like you our journey has had a few challenges from time to time as well as some unexpected successes along the way. We have now entered the world of adult services and are beginning to become aware of the gaps in funding and services. As we prepare our case for our upcoming appeal with PDD regarding appropriate funding for our son we are prepared to put our son's needs first. We have been at this point more than once along our journey and we are prepared to fight for what our son needs to be fully included and an active participant in the community he supports and lives in.

There is much we need to prepare for as parents. We need to make sure that when we are no longer here that there are adequate supports in place for our loved one with autism. For our family we need to reassure his older sister that she will not have to plan for or take care of the financial burden of looking after her younger brother as she recently disclosed to us by putting a plan into place for him now. We need to make sure we have an appropriate housing option in place and develop a network of support for him when we are no longer around to do it. It is a lot to think about and plan for.

During our journey we have called upon the Autism Society of Edmonton for information and support when we needed it. The issues that concern our family and yours are also issues that are of concern to the Autism Society of Edmonton. I now serve on the board of directors for this organization to show my appreciation for all of the years of support they provided to us when we needed it.

I am honoured to work with this important locally founded organization as they continue their important work in helping families and communities embrace and support people on the autism spectrum throughout their lives.

Whether you are just starting your journey, nearing the end or somewhere in between the Autism Society of Edmonton is fighting your fight every day. We know there is much work to be done. We see the need for adequate respite, more vocational, post secondary and housing options just to name a few. The work to keep educating and advocating on behalf of our loved ones with autism will continue today, tomorrow and in the days to come.

I wish you well wherever you are in your journey!