Autism

From a Father's Point of View

By Stuart Duncan

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This version was published on 2012-08-20

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Preface

There are no hard numbers to quote you but it's fairly safe to say that the majority of parents writing or speaking out about autism are moms. I'm sure a whole other book could be written about why that is but instead, I'd rather just write about my experience… a father's experience.

When my son Cameron was diagnosed at 2.5 years of age, my wife and I just naturally took to our roles without discussing, deciding or even thinking about it.

She became the therapist, educator, assistant and nurturer, accompanying Cameron to each appointment, learning what each appointment had to offer and then reinforcing those appointments while back at home. She sat with him each day, working with him, playing with him and just being with him.

While I also played and enjoyed my time with him, my "work" took me more towards the information highway, reading up on articles, books and any other information I could get my hands on. I found a lot of parents just like me on various social networking sites, through a bunch of different blogs and even through local charities. I contacted a few with a simple message: "I'd like to help."

Over the next several years, we continued along those lines, working as a team; my wife helping me learn what the therapists taught her and my son and me helping her to learn the latest research, discoveries and methods of other parents.

What I've come to realize is that, over time, she became the input; bringing in information, and I became the output; speaking out and sharing information.

I grew a following on Twitter, Facebook, Google+ and a few other sites that surpassed 10,000 followers in total including parents, experts and autistics themselves where I could ask questions, share the latest information and relate with others either by sharing stories or reading theirs.

It's been an amazing journey and I'm just getting started. In this ebook, I'd like to share some of that journey with you.

Introduction

This book is an account of what I and my family went through in getting our son diagnosed, the process since then as well as some rather huge life changing decisions we've needed to make.

It also contains a bunch of articles from my popular blog Autism From a Father's Point of View[1] that, I feel, really exemplify what I've learned and experienced by being on this journey with my son. So some of it may feel a bit scattered or random from one chapter to another in some places.

My blog started out as just a place to collect my thoughts, hense the domain name (StuartDuncan.name). It was just me. But over time, I wanted to actually write about something. It had to be something that I knew enough about, that I could continue writing about for years and it had to be something that I felt deeply about.

Then my son was diagnosed with autism.

It was actually my wife that suggested that I should write about autism. I had already been reading blogs by other parents and was gathering up a pretty good knowledge base from all of the articles and books that I had been reading on the subject. When your child is diagnosed with a disability, you do that.

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[1] http://www.stuartduncan.name

I had always felt good about reading those other blogs on the internet. They gave me a sense of kinship. I realized that I wasn't really alone after all. And I learned a lot of neat things along the way too. I wanted to do that. I wanted to be able to give back.

Now I want to do more. I want to reach out to more people and hear back from more people. I want people to feel good, not defeated. I want people to look for the positives where previously they could only see negatives. I want people to smile even if they feel like all they can do is cry.

Autism is a real struggle, there is no doubt about that. But over time, I've learned to look beyond the autism, both within my own son and myself. My son is who he is, with or without autism. The real difference it's made is in me. In a good way.

I'd like to share some of that with you.

The Diagnosis

The Signs

From the time that Cameron was able to sit up on his own, we started to notice little things that were not quite what we expected. For example, we'd put toys around him for him to look at, play with and just generally be curious about. You know, as children do. But he wasn't curious about them at all. He didn't want to play with them either.

Cameron would take each toy, one by one, and move them all over to one side of his body. Once every toy was beside him, he'd move them, one by one, over to the other side of his body. And he'd repeat this, over and over again.

We just thought that it was something he liked to do, kind of odd but cute and we didn't question it.

As he progressed we'd find him lining up his cars or turning them over on their hood so he could spin the car or the car's wheels. He'd do this for hours.

He would separate all of his building blocks or legos by colour. He would stand in the middle of the room, one toy in each hand and slowly move them across his face, right in front of his eyes and then outstretch his arms to the side. Then he'd slowly move them across his face again the other way and outstretch his arsm in the other direction. We called this “doing his Thai-Chi” because it looked very much like that.

At about 18 months, we asked our doctor to have him assessed for autism. We didn’t really know much about it to be honest. Due to all of these behaviours from Cameron, we just knew that something was different. He was different.

He still hadn’t said a word. He still didn’t play with his toys. He didn’t respond to his name. We wanted answers. So we started researching it and as we learned more about autism, we came to the point where we wanted only one answer... is it autism or not.

Our doctor tried to reassure us that nothing was wrong and that our son is probably not autistic but rather just a late talker. And that lots of children have peculiar quirks. Mostly he was just stalling though because the doctors that can make the diagnosis refused to see any child until they were two.

So when he turned two, we were back into our doctor’s office, insisting on the refferal. We finally got one but due to lack of funding, doctors and facilities, we had a 6 month wait. Not all that bad but this still put our son at 2.5 years old. He was half way to being 5 and his first day of school was coming up quick.

Getting The Diagnosis

At this time, my wife Natalie was pregnant with our second child, Tyler. Her pregnancy was not going well, to say the least. The last 6 months of her pregnancy was spent on bed rest. She was unable to move. The last 4 weeks were spent on bed rest in the hospital.

Because she wasn't working and times were hard, this left me working 2 jobs as well as taking care of Cameron on my own. Plus I had to take care of Natalie who was stuck in bed.

It also meant that I was on my own to take Cameron downtown to the doctors office where he would finally be assessed for autism. This is a daunting thing to do for any parent, especially when they have to do it alone. I can't even imagine how it must have felt for Natalie, being stuck at home in bed, unable to be there with us.

So I take my son into this little tiny room. It looks like a daycare center for one. I sit down and Cameron starts to play.

The doctor talks to me and then to my son. Mentions some observations and then blows some bubbles into the air.

Cameron looks at them and says "bubbles!"

Are you kidding me? All I could think was "Now you say your first word? Now? When a doctor is watching? The doctor's going to think I'm wasting their time!"

Of course, the doctor didn't think that at all and told me afterwards that Cameron is definitely on the spectrum and they'd have more for us later with the official report.

When we did get that report, it was official. PDD-NOS or Pervasive Development Disorder Not Otherwise Specified. Autism.

The emotions I skipped

In my experience, I've found that most people handle their child's autism diagnosis in one of two ways (sometimes both); they either feel guilt for having let their child down or for feeling like they will let their child down; or they grieve for the dreams that are lost, the struggles yet to come, the person that their child will never be and for the unfair nature that is the lottery of life.

I didn't get a chance to experience either of these things. It's not due to me being positive, wise or any other wonderful thing that I wish I could claim to be. The truth is, with my wife still being on bed rest, pregnant with our next child, me working 2 jobs and taking care of the family and having to now take in the reality of an autism diagnosis, I just simply didn't have the faculties to process it as most people would. I was too busy!

I asked for insights from the doctors, I did a little research on the internet, as must as I could while working, I talked to my wife and I did my best, day by day. I just didn't have the time to slow down and really think about it.

In hindesight, I suppose that was a bit of a blessing. Although I'm fairly certain that I never would have felt any guilt over it, I probably would have grieved if I had been given the time to really dwell on it. It is a difficult thing to experience for any parent.

I called it the "life yet to come flashing before your eyes" where, instead of your own life in the past flashing before your eyes, instead, this time your child's life that they haven't even experienced yet flashes before your eyes. And in that instant, you picture all the things you wanted for them that will likely never happen and all the things that you didn't want to have happen that probably will.

In a nutshell, you give up your dreams and expect the worst.

That's not how it end up playing out at all, well, for most of us. It certainly hasn't for me. But for most of us, I would imagine that's the feeling we get when we first find out that our child has autism.

So no, looking back at it, I didn't feel much, if anything, at all. I wasn’t given the opportunity. I still haven’t decided if that’s for the best or not.

Our new roles

A new position in life

When your child is diagnosed with autism, or pretty much any special needs I'd imagine, you are instantly promoted in life to the wearer of many hats.

No longer are you simply mother or father. You become doctor, psychiatrist, researcher, scientist, advocate, lawyer, moderator, speaker, educator, student, investigator, therapist and so much more.

Like many parents, we had heard of autism but didn't know very much about it.

We didn't know how many children were diagnosed with it, we didn't know just how wide ranging it is, we didn't know about the sensory issues and we certainly didn't know what it was going to mean for us as parents raising an autistic child.

Considering just how wide ranging autism can be and just how different every child can be, a doctor can't really do much to prepare you either. They tried their best but for the most part, we felt like we were given the dagnosis and then left to fend for ourselves.

So that's what we did.

Team positions

I have great admiration for single parents or for parents who are forced to do it on their own due to their partner's denial or lack of support.

I say that because I couldn't imagine what it would have been like for me if I didn't have my wife with me.

We each took to our strengths immediately, without even saying a word to each other. It's as if we just each knew what to do and formed a really great team, without even trying.

I, being the techy that I am, took to my computer and read as much as I could. I got in contact with other parents, charities and even journalists right away. I found out as much as I could about everything and we even found ourselves in the local newspaper as part of the Autism Awareness day stories.

I discovered what all the theories were as to what causes autism and I also learned what people were trying for treatments, and even cures. I quickly learned that some things, while they sound like they hold promise, are actually quite dangerous and really have no evidence backing them.

I could write a whole other book just about my discoveries and my opinions of them. But that will have to wait for another time.

My wife, on the other hand, took a much more hands on approach. She found every local service and organization there was in the area and started scheduling appointments and setting up therapy schedules.

The most wonderful thing she did was, when the therapist would tell her to wait in the waiting room while they worked with our son, she would say no and insist on going in with them.

The reason she did that was so that she could learn what it was that they were doing. Appointments were generally weeks apart, or longer, and she wanted to continue working with Cameron every single day so that when the next appointment rolled around, he would have a good handle on what it was that the therapist wanted him to do. This helped him progress much more quickly than if we had no idea what the therapists were doing.

If I could give parents any advice at all it would be to do what my wife did. Get involved and carry the therapy forward. Not only does it really help your little one progress but it also makes for a great bonding experience. Plus, it wasn't always therapy. Sometimes she'd read with him, teach him colours, letters or numbers and so forth.

This also provided her with quite the binder full of useful information because the therapists, once they saw her progress, were more than willing to offer up information and lesson plans.

Putting it all together

From time to time, I would tell my wife about the things I learned while she'd tell me about how therapy went and what to do with our son to continue it forward. She would read some things I gave her and I'd sit in or even do the lessons with my son. It wasn't a total separation by any means but it was a working system.

It wasn't long after his diagnosis that I started my own autism blog, eager to share my experiences with my son and things that my wife learned from therapy. Things that I could pass along, not so much in an effort to inform but maybe to find those that can relate and to give them some peace of mind.

Sometimes a parent would write in with questions that were therapy related and I didn't have an answer too. Well, my wife did! So I'd ask for her input and have something to respond with.

It wasn't so much that we both split off and did our own things that made it work, it was our coming together afterwards to share and discuss it all.

I really think that is what has made us a good team. And that's really what you need to have if you're going to see any real positive progress. Unless of course, you are a single parent or you're just that awesome that you don't need your spouses help.

Doing different things without collaboration will not work. One person doing all the work while the other is unsupportive or in denial will not work.

You have to be a team.

Moving the family

I’ve lived in a lot of different cities in my life. All of them in Canada but still, there have been a lot. There was one city in particular though that I told myself that I’d never live in. It’s way too far away from everything, has very little there, it’s extremely cold in the winter and extremely hot in the summer. I hate just about everything about it.

That’s where I’m living now.

The center of the universe

When Cameron was born, we were living close to Toronto. Because Toronto is the largest city in Canada, we figured we were in a prime location to handle our sons diagnosis.

It turns out that we were wrong.

From the moment that we even asked for the assessment, we kept finding ourselves on wait list after wait list. We had to wait until Cameron was 2, then we had to wait for our doctor to make the referral, then we had to wait 6 months for the actual appointment and this is just to get the diagnosis. It got worse after!

From there, we had to wait several months for speech therapy, more months than that for occupational therapy and for IBI (the Canadian version of ABA[2]), we had to wait 3 years. THREE YEARS!!

That would make Cameron 5 and a half by the time he even started, which, while not “too late”, we would have missed the most valuable character building and personality establishing years of his life.

We didn’t wait for speech therapy, electing to him put him at our own cost at a location that didn’t have a wait list. But we couldn’t afford the $150/hour for very long.

It became worse as the years went on. As Cameron worked hard and we worked hard with him, he progresed well. Which should be a great thing. right?

The thing is, in the beginning, the Toronto Discrict School Board told us that Cameron qualified for special education, a teacher’s aide and all the good stuff that we knew he’d need.

As time went by, however, those promises went away, one by one. It would seem that Camerons progress was only hurting his chances at getting any kind of support in school.

By the time Cameron was 4 and ready to begin school, there was nothing left. He was to be placed in a regular school, in a regular classroom with a regular teacher and regular classmates.

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[2] http://en.wikipedia.org/wiki/Autism_therapies#Applied_behavior_analysis

He wasn’t ready for that.

The decision

Early in the year, my wife and I started doing a search across Canada, looking for a school that would accomodate Cameron.

There had to be something, somewhere, where he could do well and that wouldn’t be too expensive.

In April, my wife found it, in her home town. The town that I dreaded. The town that I swore to myself that I’d never live in.

A little school named Golden Avenue Public School was just starting a brand new program where 3 classrooms were dedicated to children with autism.

Each class had a teacher with knowledge in autism as well as 2 or 3 aides to help out. Also, the class sizes are kept down to just 5 or 6 children.

This gave the children the one on one attention they needed. This also meant that they’d be able to learn at their own pace, in their own way and on their own terms.

It was perfect but so very far away.

The good news is that most of my wifes family lives there so we had a place to stay if we did decide to make the move.

So, in April, my wife made the 10 hour drive with both Cameron and Tyler to go to the school and discuss our options. They evaluated Cameron, they discussed his needs and our expectations and right then and there, it was decided... this is where Cameron would go to school.

So in June we made the decision to move. But school was starting in September.

We had a lot to do.

The move

We made the final decision in June to make the move. We rennovated our house in July and I lost my job. We packed up the truck and moved in August. Cameron started school in September and then, from 850km away, we sold our house... at a loss.

That's a lot. Let me break it down for you.

After my wife returned home with the boys in April, we discussed whether or not we could really make such a huge step. Selling our house, moving our family, leaving my family behind, our friends... it was a huge decision. But we didn't have time.

We came to the conclusion that we were looking for a school for a reason. We knew what we needed to do. This was for our son and for his future.

So in June, we made the decision to get our butts in gear and start the long process towards a short move.

Towards the end of June and for all of July, we rennovated our house as best we could to ensure it would sell.

And this is where a big kudos goes out to my wife because she did the brunt of the work on the house and took care of the boys at the same time while I worked my 9-5 job. When I was done my shift, I would help out in the evenings.

That didn't last long though because so much was going on with my life and I was so tired and a whole host of other reasons that will likely come across as excuses, I lost my job. So we had no money, no income and still had more rennovations to do and the move itself yet to come.

Thankfully, with great friends and family, we were able to pull it off. But not without some sacrifices.

We had to put my sofa on the curb for someone else to take. We had to give away our fridge, stove, bbq, eliptical (exercise machine) and several other possessions. What we couldn't give away, we threw out.

With only what we could fit into the back of a U-Haul truck, which we paid for with our credit card, we put the kids in the car and drove away from the lives we had in August.

We put most of what was in the truck into a storage bin (again, more credit card bills) and moved in with my my wifes parents. Yes. The in-laws.

We weren't prepared to be moochers and they weren't prepared to have a live in famiy and they certainly weren't prepared to have a baby that cries often, an autistic boy that had meltdowns daily and all the regular stuff that a family can bring such as toys everywhere.

Still though, they made the most of it. We made the most of it. And we will always be eternally grateful for the hospitality and help they gave us when we really needed it.

So anyway, September rolls around and Cameron heads off for his first day of school. At the same time, we get word from our real estate agent that a buyer is interested in our house. A few details later and our house is sold, while we're not even there.

Sadly though, we had to sell it at a loss. That means that the guy that bought it from us paid less than what we still had to pay on our mortgage. So we borrowed the money from my grandmother to pay the remainder and are still paying her off to this day.

It was worth it

So we have insane credit card debt that we're still paying for 3 years later. We still have a loan with my grandmother that we're paying for 3 years later.

We have old, hand-me-down furniture and appliances instead of our nice new stuff that we used to have. We're living in a not-so-great appartment instead of a nice house like we used to have.

Also, I don't get to see my family much anymore and we never get to see the friends that we left behind.

All that and more yet I can still say, with complete confidence and certainty, we made the right decision.

Cameron is excelling now in his school work. He is already being integrated in with the other classes at the school. He is just doing so very well.

I even caught him talking to a neighbor boy the other day, on his own. That's huge!!

I am also very confident that if we hadn't made that move and were forced to put Cameron into the regular school, it would have been catastrophic.

I tell people often about the sacrifices my family has made and it's usually met with one response: "It's great that you could do that but we could never just move somewhere else like that."

To those people, I have to ask: "What makes you think it was any easier for me?"

If it's for your child, you do what you have to do. It's worth it.