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Celebrating Ian

A Unique Parenting Experience

ANN DOUGLAS

We're in the grocery store, picking out produce, when my 16-year-old son's cellphone rings. Ian runs a small-engine repair business out of our driveway and fields all kinds of phone calls from would-be customers. A few minutes into the conversation, Ian wraps up the phone call rather abruptly: "I told him I didn't think it would work out between us and I wished him all the best in finding someone else to repair his snow blower," he explains, slipping his cellphone back into his coat pocket.

Ian is one of the most self-aware people I know. He has a remarkable appreciation of his own strengths – his rational mind, his ability to diagnose and fix pretty much anything, his February-dry sense of humour –

and an even more remarkable ability to work around his key weakness: the fact that he finds human beings more puzzling than machines.

He has endless patience with high-maintenance machines. High-maintenance people? Not so much. He chooses his friends and clients wisely and, as the old expression goes, he doesn't suffer fools gladly – hence his tendency to give would-be clients who smell like trouble their walking papers in advance.

He isn't merely okay with who he is – a guy who loves downhill skiing, fixing machines and performing in plays, and who also happens to have been diagnosed with Asperger syndrome (an autism spectrum disorder). *He totally likes who he is.*



My heart overflows with love and gratitude because I have had the privilege of raising this child.

"I love myself," he announced to his father and me recently. "I guess being comfortable in my own skin is one of the many gifts you gave me." It's clear he's being both honest and slightly sarcastic at the same time – a classic Ian communication. Do I need to point out how much I love being this kid's mom?

It wasn't always this simple, this easy, this fabulous. In fact, for a while, things were actually quite awful. When Ian was a little kid, he struggled – a lot. And when he struggled, we struggled right along with him. He had a really tough time learning how to talk. For the first three-and-a-half years of his life, he spoke in vowel sounds only – something that made his speech largely unintelligible to anyone outside the family.

He also struggled with basic motor skills that most kids take for granted, such as learning how to cut paper with a pair of kids' scissors or learning how to ride a tricycle.

He didn't have a lot of friends. Correction: he didn't have any friends. But he didn't seem to care about not having friends. This was a kid who preferred the company of adults. We (his father and I) were the ones who worried about his lack of friends. And we worried – a lot.

Ian was able to cope fairly well until he started school. That's when things went from being difficult to being too much for him to handle. We noticed a significant change in Ian, starting in Grade 1. He went from being a happy kid to being an angry kid. By the time the school year wound up, he had been suspended six times and he was describing himself as one of the "bad kids" at school.

We started Ian at a new school. He managed to hold his own for a few more years, until the year he started Grade 5. Then, the situation reached the crisis point again. Ian was having a great deal of difficulty coping with any disruption to the regular classroom routine. Field trips were a disaster. And he was totally mystified by the unwritten rules of friendship. An incident of taunting erupted into a violent outburst and we were asked to withdraw Ian from the school.

Ian was heartbroken. He may not have been the most social kid on the planet, but the few friends that he did have all attended this one school. He begged the school principal to reconsider her decision. When she told him that her decision was final – he would have to leave the school – he told us that his life was over. I don't know who was crying harder – him or me – as we lugged his belongings out of the school.

We hired a full-time tutor to work with him for the remainder of that school year. The key item on the agenda was helping Ian to rebuild his fractured self-esteem. At the same time, we continued to pursue a psychological diagnosis. (Our pediatrician had advised a wait-and-see approach when Ian was younger because his symptoms didn't explicitly point to any clear diagnosis.)

Extensive psycho-educational testing finally yielded some answers, which our pediatrician supported. The diagnosis was Asperger syndrome (a type of autism spectrum disorder that is characterized by weak social skills, difficulty adjusting to changes in routine, motor skills difficulties and preoccupations with particular areas of interest) and ADD (attention deficit disorder).

Ian took the diagnosis in stride. The ADD part was no big deal. His two brothers shared the same diagnosis. And as for the Asperger's part? "I'm fine with everything but the name," he scrawled on a note to me. "Ass burgers."

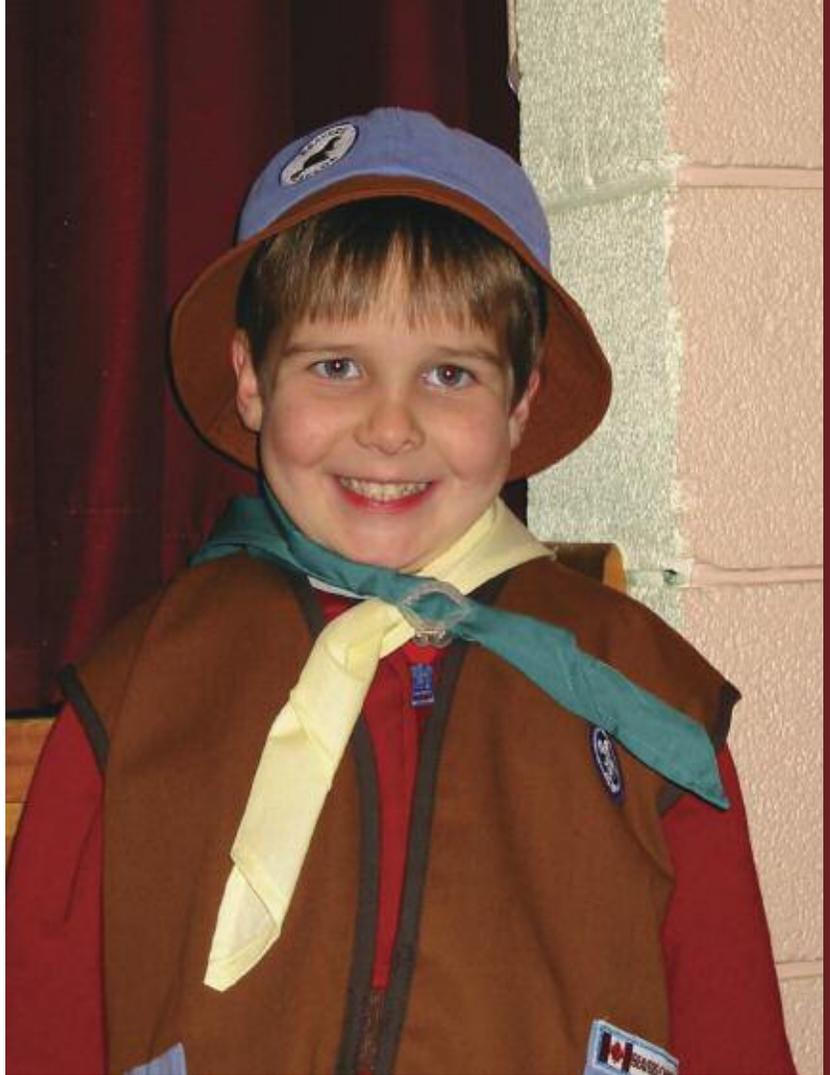
We were also trying to wrap our own heads around the Asperger's part. The diagnostic criteria didn't totally fit Ian, but it was closer than anything

else we had come across. And we worried about some of the doom-and-gloom prognoses that we discovered on certain websites. We wanted so much more for our son than what we were being led to believe might be possible on either the employment or romantic relationship fronts. So we chose not to allow our thinking to be limited by someone else's ideas about what might be possible for our son – someone who had never even had the pleasure of meeting him. That became the guiding force in our parenting: maximizing potential and possibility.

It took two more tries before we finally found a school that was the right fit for Ian – a school with caring administrators and teachers who gave Ian the gift of unconditional acceptance and support. Things started to get a whole lot better. He made friends. He joined clubs. He learned how to ski!

That's not to say that Ian's school life suddenly became perfect. He continued to experience occasional episodes of bullying. But, at this new school (the school he continues to attend to this day), anti-bullying policies were so much more than just words on a page: they were actually backed up with consequences. It also didn't hurt that he ended up going through a growth spurt. A stocky and formidable six-footer, Ian now towers over most of his former tormenters. Physical size can be a powerful deterrent.

He stands out in any classroom, both because of his size and because of his outspokenness. No shrinking violet is my son. He doesn't mind being on the unpopular side of an opinion if he feels that there's an important cause to be championed. A few



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Asperger's and autism

- Asperger syndrome is a chronic neurodevelopmental disorder that strongly affects social interaction and communication, often including a restricted range of behaviours or interests. Asperger's is an autism spectrum disorder – a range of conditions that has been estimated to affect one in every 150-160 children.¹
- Children living with autism can experience delays in certain areas of development, often characterized by impaired reciprocal social interactions, restricted and repetitive patterns of behaviour, dependence on personal routines and an intense pursuit of circumscribed interests relative to their peers.²
- Many children with autism exhibit advanced development in certain skill areas, which can include non-verbal reasoning, reading, drawing, memory, music, perceptual motor skills, computer skills and visual-spatial abilities.³
- While the exact cause has not been determined, there is a growing body of evidence supporting a genetic basis for autism spectrum disorders. Researchers continue to investigate many other possibilities including pre- and post-natal development, environmental factors and deficiencies in the immune system. What is known is that autism is not infectious and does not result from parental style or behaviour.⁴

¹ Health Canada, “About Autism Spectrum Disorders,” *Health Concerns*, accessed February 24, 2014, <http://bit.ly/19h2fVd>.

² M.R. Woodbury-Smith and F.R. Volkmar, (January 2009), “Asperger Syndrome,” *European Child Adolescent Psychiatry* 18 (1): 2-11, <http://bit.ly/1cuRra4>.

³ Autism Canada Foundation, *About Autism: Characteristics* (2011), accessed February 28, 2014, <http://bit.ly/1bG2xs4>.

⁴ Health Canada.



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years back, he became involved in efforts to prevent the closing of a local high school – even though this wasn’t actually his own high school. He felt it was important to stand up for what he believed to be right, even though he took a lot of heat at his own school for wearing a T-shirt in support of a rival school. He went to school board meetings. He helped to organize fundraisers. We couldn’t have been more proud.

I love the fact that Ian has managed to find his way in the world and that he knows who he is and what he wants. And as for all those doom-and-gloom websites that predicted that Ian – or someone like Ian – would never be capable of having a relationship or a job? He’s already proven them wrong on both fronts. Who knows what the future holds for him – or for us, as his parents, because we’ve been lucky enough to have the gift of Ian in our lives.

You see, Ian was a gift right from day one – from the moment we first held him in our arms. Eleven-and-a-half months before he was born, we had stood in a cemetery on a crisp October day, surrounded by our other three children (then 9, 7 and 5) while we said goodbye to a tiny baby girl born with a knot in her

umbilical cord. The only way we knew to emerge from that heartbreak was by daring to reinvest in life again: by making a conscious decision to have another child – the child who would be Ian.

During the early years, when we were trying to access the necessary supports for Ian, it seemed like we were giving everything we had and more to the task of raising him. I now realize that what we were giving him was actually just a loan, because the time, love and energy we invested in him have been repaid many times over.

Some see “special needs” and they see limitations. I see possibility and potential. My heart overflows with love and gratitude because I have had the privilege of raising this child. ◀

Ann Douglas is a writer (The Mother of All Pregnancy Books) and speaker who specializes in parenting. She is also the mother of four children, aged 16 through 26. Her latest book is Strengthened by the Storm, a book for parents who have a child who is struggling with mental illness. It will be published by HarperCollins Canada in January 2015. Ann’s website is www.anndouglas.ca.