

A high-angle photograph of a person's feet wearing dark, lace-up sneakers with white soles, standing on a floor made of small, multi-colored mosaic tiles. The person is wearing dark trousers. The lighting is bright, casting a shadow of the person's feet onto the mosaic floor.

Pascal van IJzendoorn & Ans Ettema-Essler

**Autistic,
quite a bit.**

**Long before
I knew it.**

VILLAGE PUBLISHERS HOLLAND

AUTISTIC, QUITE A BIT.

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Long before I new it.

Pascal van IJzendoorn & Ans Ettema-Essler

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Preface

If you were to run into me someplace, nothing about me would tell you I have the diagnosis ‘autism’. Let’s be honest: it isn’t necessarily something you see on the outside, and you can’t hear it when I open my mouth and start speaking in my regional dialect. With due pride, I am able to say that I’ve learned to participate in society. I know how to take care of myself, which – quite frankly – has cost me some time and effort. And sometimes... sometimes you’ll still catch me take one of those talked-about wrong turns, and I’ll crash pretty badly. However, at this time in my life I know that staying down on the ground isn’t an option. So, what is? I’ll tell you: getting up, considering possible solutions and restructuring everything. My goodness, I have definitely been down that road often in my 35 years of living. Yet, I think that even in difficult situations like those, my autism isn’t a permission slip for me to count on help from others. I would rather get up without metaphorical crutches. I prefer seeing these experiences as lessons to prevent me from finding myself in such situations in the future. To accomplish this, I use my qualities, skills, and tricks that I have taught myself over the years. For instance, I have highly developed thinking abilities and I’m very good at separating important from unimportant things. The narrative that ‘we, autistics’ only focus on details simply doesn’t hold true for me. I’ve noticed that I can clash with my peers – and even with my counsellors – because of my methods of thinking and doing things. In my opinion, you *are* allowed to have a different opinion on what you think you should do or do not have the right to, but that also means that I have that very same right!

As with a lot of things, autistics, too, can be very different from one another. This is usually due to our backgrounds.

How were you raised? Were you supported? How were you treated in your earliest years? If you were sheltered from the world, it's easy to imagine that taking on new challenges can be a very big step. It also works the other way around, though. If you were left to yourself a lot due to your autism, you learn to rely on yourself pretty quickly. You need that in order to face life's challenges. Sometimes, this clashes with the outside world's perspective. The funny thing is that, when it comes to autism, our society tends to have the quiet ones in mind – those who mainly focus on what they can do well. Well... that's not the case for me! With this book, I would like to make the case for autistic people who, like me, are more than capable to get the hang of many traits and skills. You can do this by, for example, focusing hard (and for a long time!) on someone you consider to be amazing at something. By observing the other, we learn, we practice, and then we copy the behaviour. And if we're able to do this thing more than once, I would say it's a developed skill.

You can also see this book as an inner journey in the *World of Pascal*, where there are different laws, where a different fixed structure exists, and where you'll be met with an unprecedented hunger for knowledge and skills.

‘Who am I?’ the Autist Wondered...

It's taken me quite a few years before I knew that I was born with autism. In hindsight, I'm surprised that it took as long as it did before a psychologist or psychiatrist came to the right diagnosis. As a result, I have been labelled as many things over the years. Since receiving my autism diagnosis, many puzzle pieces fell into place and I've learned to understand myself better. I have found answers to questions I'd walked around with for a long time. Why was I able to do the most complicated chore by myself, but was it doomed to fail if I had to do the same task with someone else? Why am I such an autodidact, hungering for knowledge and experience in different areas? I've found an explanation for many of these questions. It's also caused me to develop my own meaning of the phenomenon called 'autism', which can deviate greatly from how many autistic peers and counsellors feel. Yet, that opinion is true for me and determines the way in which I view life. And what's more... It's how I experience it!

As a little boy, I must've already shown some signs of autism. I had a fairly weird way of walking, because I used to walk on my toes. I also preferred playing by myself, though years later I would copy everything my younger brother made with his Legos. (Of course, I did design the perfect version of his creations.) It also became clear from an early age that I wanted my life to go my way. After my parents divorced, I truly felt like the head of the household. It was my way or the highway, and my mother and my little sister were supposed to listen to me. And if they didn't want to listen to my raised boyish voice, I always had my hands and feet with which I could deal pretty hard kicks and punches. My mother remarried quickly; she even became pregnant again soon after. These changes

were very hard for me to take. Suddenly, two new inhabitants entered my kingdom: one who thought he was going to govern the place (stepfather) and one who I was supposed to love (half-brother). I decided to banish them from my world and see them as mere passers-by in my life. Many must have referred to me as having a huge ego, despite my small stature. In fact, I heard the word 'narcissist' drop regularly in the year that followed. Both statements refer to several diagnoses that I've been dealt during my counselling trajectory. They made me doubt at first, but since I got my autism diagnosis, those doubts have faded away completely. I now understand that my egocentrism was a way for me to keep my head above water. Focusing on myself was the only way in which I could make situations bearable.

In elementary school, I irrevocably had to face 'the other', as well as the heads of my class and school. At home, my mother would often listen to me in order to keep the peace. In school, however, my behaviour didn't fly. I had one teacher who very quickly showed that we didn't get along. She tried to bring me to heel with a heavy hand, but it didn't work. It led to my mother meeting her for frequent talks about how the 'school situation' could be improved. After we moved somewhere else in the same town, I had our principal in front of my classroom. Initially we got on quite well, until he had to face one of my more difficult sides as well. He tried to get through to me by means of punishment, which obviously turned into a battle between the two of us. That battle only ended when I went left elementary school.

During that period, I had a hard time communicating with others. I mostly responded from my own world and wouldn't let anybody in. It was my way to survive and to keep stimuli at bay so I wouldn't drown in them. Punishments, heavy conversations, or arguments couldn't harm me as long as I was safely locked away in my own world. I kept the door shut, so

it wouldn't be opened too often. Communicating with another, which is quite a thing for people with ASD (Autism Spectrum Disorder), is something that I learned during my middle and high school years. I suddenly understood that, by tickling someone in just the right way, your 'profit' could end up being more than your investment. And honestly, I quite liked being able to get along with people. My negative sides were overcompensated by all the positive things I did for them. I'd say that these years were my luckiest ones during my school career.

Yet, even this was ruined by the big, bad world. My stepfather made us move to an entirely different part of the country for his job, which meant that I had to let go everything that had given me such joy. It happened despite my resistance, anger, and frustration. I had to come along and couldn't stay in my old town. For me, it was as if the anchors that I'd dropped here were removed, which made me lose control of my lifeboat. I found myself adrift and disappeared in my own 'autistic' world. It hurt my mother in particular to see this happen; she understood that the move meant my social life was gone. She tried her best to find me new friends, not knowing that she'd driven me into a den of thieves with all sorts of addictions in doing so. After a while, she saw that my problems had worsened, and that only professional help could save me. And that is how I started my journey through the wonderful track circuit of healthcare, which finally ended with my autism diagnosis when I was thirty-one.

When I walk through town, nobody can tell that I'm autistic. This might seem beneficial, but it really doesn't have to be. It can lead to suffering. For instance, a physical therapist or doctor doesn't understand that I have difficulties being touched. I hardly keep in touch with family, especially in the same way I see people around me engage with theirs. My mother and

I have the occasional phone call, and we'll see each other a few times per year at most. Maintaining friendships doesn't come easy to me, which means that a lot of friendships have perished. Apparently, my attitude in a friendship differs from the general expectation. I won't call you unannounced to ask how you're doing. It's also very likely that I won't send you a birthday card, because I simply forgot to. And shaking my hand or kissing my cheek when you meet me? I don't think so. In short, I don't really engage with social rules. Anyone I met during my lifetime who did abide by those rules disappeared from my life ages ago. It's safe to say that only the hardcore base remained. These people take me how I truly am. This small group of people knows that I have autism. I told them about it, and they have experienced this in our friendship more than once. They know my personal manual. If I do something that's strange to them, they aren't afraid to ask me directly. For the rest of the world, my autism isn't only completely unknown, but also invisible. I'm not missing any limbs (thank goodness), and I can walk, see, and hear fine. It's safe to say that I can move through our society fairly well. On the outside, you can hardly see anything related to my autism, and even on the surface my life isn't too different from the average Dutch person's. I live in a house with my girlfriend and (step) daughter, I go to work at an elementary school regularly, and I drive around in my car to get groceries.

In my private life, everyone knows about my autism, but that wasn't the case for my employer – 'the school'. A few years ago, I started volunteering as a handyman at a school in the neighbourhood. It's a nice school that really has a place for every religion, skin colour, and... well... most diagnoses. When I started working there, I only notified the principal of my diagnosis and didn't tell my other co-workers. Until...

As in most Dutch elementary schools, the final year of school in

2016 started with a camping trip somewhere in the province. In the early summer, we settled in a small coastal town called Wijk aan Zee. A group of teachers and I assisted during this trip, organised at a spacious location suitable for large hoards of early adolescents. After our first day of hard work, all of the adults were relaxing with a beer or glass of wine in hand and we finally had time to catch up. We noticed that we weren't the only school on the terrain. In fact, there was a special needs group with autistic kids up to the age of 12. One of the teachers in our group mentioned that she didn't think you could see it was a school for autistic children. I don't know what moved me to come out of the figurative closet, but I suddenly told her and everyone in our group that I, too, have autism. This heart-to-heart turned out to have a huge impact. Full of disbelief and surprise, one after the other told me that they'd never thought I did. This nice man who was so good at being friendly and small talk couldn't be autistic... could he?

Their response made me decide to tell more people about my type of autism. How exactly does my brain work? How do I manage to keep myself grounded in our society? I could write books about it, and that ultimately made me decide to write one. I did have a little problem, though: I'm also dyslectic. I would never be able to put pen to paper and write down all that I'd been through and the rich experiences that I'd had. At the same time, I had been considering writing a book for some time. Until dear Ann called me in early 2016. In her private life, she messed up with someone pretty badly, and she realised that it might have been due to her lack of knowledge about autism. She needed information and answers. Where did she go wrong with this person? She couldn't find her answers on the internet, so she turned to the one person with autism that she knew: her friend's partner. She did the bold thing and picked up her phone, told me her story, and asked me her questions.

She absorbed everything I told her, a method I recognised as not dissimilar to my own. I ended up on Ann's couch soon after, and I realised that Ann wrote books. A few weeks later, I decided to be the one to take the next bold move. I called to ask her if she would help me write this book. I knew she wasn't afraid to ask questions, both the clever and the stupid kind. Fast forward to a month later, and we sat across from each other – awkwardly – and just started working. We started on small fragments of text and developed them into real chapters. And after two years, this book was born.

The purpose of this book is to enrichen our society with ways of looking at autism. 'Having autism' isn't a disease; it is an actual disorder with your brain at its roots. If you were able to open the top of your head, like the hood of a car, you would be able to see that certain 'cores' in the *amygdala* (for instance, your emotions) don't cooperate well with other parts of your brain. You function differently than the average person. This doesn't mean that your quality of life is less, though. You can build a life with autism that looks pretty akin to the average person's life.

I think it's an odd thing to identify *with* your disorder, saying that you are an autistic. You're a person, happy, sad... But to *be* an autistic? I know there are peers who do experience it in this way, and as such choose to identify with their disorder completely. Not this fella. I think autism determines part of your identity, which – combined with your personality, knowledge, and skills – makes you into an individual. Autism doesn't always affect intelligence, either. For example, there are highly intelligent people with ASD, who are able to camouflage their lack of social skills with their intelligence. Autism is different from other disorders in that it comes with a strongly developed inner world. I call it my 'autistic mode', which is switched on when I experience over-stimulation. It's a kind of locking device that keeps stimuli out as much as possible.

This creates a 'safety mode' with which you function in the outside world. You are there, but you're also kind of not, because only the 'base me' is present without all of those learned skills and gathered knowledge. That part of myself has simply fallen away for a while for both me and my environment. This enables me to survive an ocean of stimuli, so that I can recover in my own world. Often in bed and preferably asleep, I can't be reached by others. At a certain point, I'll be back, complete in all that I am.

I would like for a future world that gives me the time and space to recover. Not just to me, though, but to others in our world who – like me – stay in their own safe haven for a while sometimes. We are different, but who isn't?

TIPS

These tips are helpful for everyone with an ASD diagnosis:

- Autism (autism spectrum disorder, ASD) isn't a disease; it's a disorder
- It doesn't determine who you are; it's only part of you as a person
- Autism doesn't say anything about your knowledge, skills, or intelligence
- Autism knows an inner world that serves as a 'recovery space' from yourself