

## Intro: Invisibly different

Through the tunnel you walk out of the aeroplane. The past ten hours you sat in a cramped seat, ate an undefinable meal and watched *Kung Fu Panda*, because you didn't have anything better to do anyway. You'd wanted to sleep, but thanks to the baby three seats down that was only a partial success. Now you're here: the other side of the world. Billboards are calling incomprehensible messages out at you, and even the bathroom is something to behold: thousands of buttons, bells and whistles. The musical note provides a noise that might be construed as cascading water and what you thought to be the flush button, turned out to be the setting to wash your behind. A lukewarm trickle sprays up. Eeew.

Past customs you're being picked up. You hold out your hand, but it's not taken. The person in front of you bows. You try to make eye contact, but the man in uniform merely looks down. Just as you're about to open the taxi door, it opens of its own account. From the back seat you look through the heavily stickered window, past the blaring television screen at the back of the headrest of the chair in front of you, out the window.

Neon billboards everywhere. 'Nihon e yokoso!', the driver says. Silence. The driver thinks, and says: 'Werukomu tsu Djapan!'

Inside half an hour you probably broke dozens of social rules. You feel like an alien, like a bull in a proverbial china shop. You're tired, and overstimulated with all the signals that are fired at you. Signals you only rarely understand. Thankfully you have an ace in the hole: you're a foreigner. You're clearly *not* Japanese, so nobody blames you for your mistakes.

But what if you *do* look Japanese? Ah, different story.

That's what autism feels like to me.

Autism, that's what I have. You can't tell on the outside. So when I tell people about it, that's what they say to me all the time: 'But... You don't look autistic at all!'

## Chapter 1: An alien in Tokyo

There I am, in Tokyo. The reason you feel like an alien here, is probably the exact reason why I feel so at ease here. I'm an alien everywhere, but in Tokyo I have an excuse. A visible excuse for why I'm different, being my 1.83 meter tall Western appearance. The fact that my awkwardness is usually not caused by my *gajin*-ness (*gajin* is the Japanese word for stranger, foreigner), escapes everyone. It also helps that my autistic quirks, such as not looking people in the eye, my aversion to touch and my love for trains that run on time and assigned 'silent compartments' on the train that are actually silent, are the most normal thing in the world here. The three months a year that I spend among the neon billboards in Japan, are a period of well-deserved rest for me.

Now, it's not my intention for this to be a rhapsody on how amazing Japan is. I can go on about it for hours (because hey, autistic), but as far as I'm concerned you can buy a good old travel guide for that, or look up the *Abroad in Japan*, *Only in Japan* and *Begin Japanology* videos on modern day YouTube. This book is about autism.

## **Circus horse**

‘Autism – That’s being able to count matches really fast, and know that August 7<sup>th</sup> 1984 was a Tuesday?’

Most people in The Netherlands have somewhat of an idea of what the term autism entails. If you yourself have autism, or know someone who is autistic, I’m assuming your idea is reasonably correct. If you got your information from tv, I’m not so sure.

In the age of advertising revenue, social media and people with an average attention span of three seconds, network executives look for the extremes. When they’re looking for someone with anorexia, the preference goes to someone weighing 28 kilos. Need a teen mom for tv? Only if it’s one living on home brand energy drink and rollies. And if the subject is autism, then people who have recreated three German cities using model trains, Eiffel towers out of tooth picks, someone who can draw an accurate picture of New York after a single helicopter flight, or at least someone who can for any date calculate at lightning speed if it was a Tuesday or a Wednesday, please. Autistics on tv are usually a kind of circus horse.

If this also is the image you have of autism, I’m afraid I have to disappoint you. The only reason I know August 7<sup>th</sup> 1984 was a Tuesday, is that it’s the day I was born. I don’t have any circus horse talents, and that goes for most autistics by far. Also, I don’t want to call every hobby that got out of hand a talent, because anyone can become good at building Eiffel towers if they, due to a lack of work and a social life, have the luxury to spend a thousand hours at that.

While one autist builds Eiffel towers, the other one struggles to fit in in the workplace. Often times just as complicated, but a lot less visible. Maybe that is my talent: to appear normal. I’ve gotten pretty good at it by now, if I may say so myself.

## **Autism according to the DSM-5**

The criteria for an autism diagnosis are described in the DSM-5: The *Diagnostic and Statistical Manual of Mental Disorders*, 5<sup>th</sup> edition. Or: the Junior Woodchucks’ Guidebook, but for psychiatrists.

### **DSM-5 classification criteria for the autism spectrum disorder**

- A. Persistent deficits in social communication and social interaction across multiple contexts, as manifested by the following, currently or by history (examples are illustrative, not exhaustive; see text):
1. **Deficits in social-emotional reciprocity**, ranging, for example, from abnormal social approach and failure of normal back-and-forth conversation; to reduced sharing of interests, emotions, or affect; to failure to initiate or respond to social interactions.
  2. **Deficits in nonverbal communicative behaviors used for social interaction**, ranging, for example, from poorly integrated verbal and nonverbal communication; to abnormalities in eye contact and body language or deficits in understanding and use of gestures; to a total lack of facial expressions and nonverbal communication.
  3. **Deficits in developing, maintaining, and understanding relationships**, ranging, for example, from difficulties adjusting behavior to suit various social contexts; to difficulties in sharing imaginative play or in making friends; to absence of interest in peers.
- B. Restricted, repetitive patterns of behavior, interests, or activities, as manifested by at least two of the following, currently or by history (examples are illustrative, not exhaustive; see text):
1. **Stereotyped or repetitive motor movements, use of objects, or speech** (e.g., simple motor stereotypes, lining up toys or flipping objects, echolalia, idiosyncratic phrases).
  2. **Insistence on sameness, inflexible adherence to routines, or ritualized patterns of verbal or nonverbal behavior** (e.g., extreme distress at small changes, difficulties with transitions, rigid thinking patterns, greeting rituals, need to take same route or eat same food every day).
  3. **Highly restricted, fixated interests that are abnormal in intensity or focus** (e.g., strong attachment to or preoccupation with unusual objects, excessively circumscribed or perseverative interests).
  4. **Hyper- or hyporeactivity to sensory input or unusual interest in sensory aspects of the environment** (e.g., apparent indifference to pain/temperature, adverse response to specific sounds or textures, excessive smelling or touching of objects, visual fascination with lights or movement).

- C. Symptoms must be present in the early developmental period (but may not become fully manifest until social demands exceed limited capacities, or may be masked by learned strategies in later life).
- D. Symptoms cause clinically significant impairment in social, occupational, or other important areas of current functioning.
- E. These disturbances are not better explained by intellectual disability (intellectual developmental disorder) or global developmental delay.

In short, what it comes down to is that someone who has autism has trouble with communication and social interaction, and has typical behaviours and interests. This needs to always have been the case, it needs to be a real burden and there is no other underlying cause.

I will later go into more detail about the aforementioned symptoms, but I already have one major criticism: this list clearly reasons from the point of view of a neuro-typical (non-autistic) person. The limitations in communication and social interaction are listed at the top as most important characteristics, because that's what an outsider notices first. Of course, that outsider, in the form of a psychiatrist, is also the one who has to make the diagnosis. But if you ask people with autism what they struggle most with, it's usually overstimulation (the last point in category B) they mention first.

## **My ass**

If you're thinking, I've heard of autism, but also of Asperger, ASD, PDD-NOS, so what is all of this? Since the DSM-5 came out, everything is called 'autism spectrum disorder'. So Asperger and PDD-NOS no longer exist as diagnoses but are included in the umbrella term autism. ASD is the abbreviation for autism spectrum disorder, and in Dutch it's ASS (for 'autismespectrumstoornis'). But because I find it odd to talk about my 'ass' I stick to the term autism.

## **Multidimensional vector space**

Autism is referred to as a spectrum disorder, which indicates the disorder has a range, from lower-functioning to higher-functioning autistics. However, this is putting matters a little bit too straightforward. Because would someone who doesn't speak, but does build complex computer models, be considered a higher-functioning or lower-functioning autistic? Autistics' capacities are usually disharmonic, which simply put means they're unevenly distributed. A person who seems to manage in everyday life, may experience mental problems that make life nearly unbearable. So autism isn't necessarily a line from zero to a hundred, but rather a multidimensional vector space. Go and look that up in a maths textbook.

## The Theory of Mind (and why it's shit)

A little girl is sitting opposite a stern looking lady wearing a plaid jacket. Her parents told her she's going to play, but instead of colouring she has to listen to this woman. The woman has two plastic dolls in her hands. 'This is Sally', she says, while showing the girl one of the dolls. 'And this is Anne.'

Sally has a marble in her basket. Anne has a box. The girl wonders why. 'One day Sally and Anne are playing with the marble in their house', the woman in the plaid jacket says. The girl is confused. She doesn't see a house, it isn't clear to her on which day Sally and Anne are playing. So far there's no playing at all. She still wants to colour.

'Sally is going outside now', the woman says. The girl looks at her lips. She's wearing lipstick. Orange. The woman puts doll Sally under the table. The girl doesn't understand: wasn't she going outside?

'Anne is naughty and moves the marble to her box', the orange lips say. The little girl is startled: it's not allowed to be naughty! Meanwhile orange-lip-woman lifts Sally up onto the table, and then asks the girl: 'Where will Sally look for her marble?'

The girl thinks. What's going on here? Why is Sally looking for her marble? Did she lose it? Carefully the girl looks toward the basket. Orange lipstick doesn't respond. The marble is in the box, the girl knows that.

'Where will Sally look for her marble?' the lips ask once more. If she wants to find the marble she should look in the box, the girl thinks. She carefully points at the box. The analyst seems content with that answer, because she continues on to the next question. The girl still wants to colour. Something with orange. A tangerine, or the sun, at night. The girl has autism, and according to this examination she lacks Theory of Mind.

Scientists have been searching for an explanation for autism for ages. Some with the desire to 'cure' us autistics or even creepier, eradicate us, as if we're back to the eugenics of the 1930's. Others mainly try to understand us. They don't always succeed that well. In the first half of the twentieth century for instance, people believed mothers of autistic children didn't give their offspring enough love. Thankfully that theory has been discredited and banished to the realm of fairy tales, although, as you will find out further on in this book, we never seem to get rid of them completely.

Nowadays the leading theory is that autistics have difficulty with the Theory of Mind; the ability to realise what the other thinks or feels. The Theory of Mind-theory was first presented in 1985, by researchers Alan Leslie, Uta Frith and

Simon Baron-Cohen. (If you're thinking, huh? Borat? No, that's Sacha Baron-Cohen, his cousin.)

In the research that led to the theory of the Theory of Mind, the Sally-Anne play was performed for a few children. Autistic children answered the question where Sally is looking for her marble wrong more often than the control group. Baron-Cohen and his colleagues' conclusion: autistics can't put themselves in someone else's place.

More precisely: people with autism wouldn't realise that other people think in a different manner than they do, and wouldn't be able to observe their own thoughts. It would explain why most autistics don't play games such as 'playing house', and why they wouldn't be able to lie. Personally I have always had my doubts about this theory, as do many other autistics.

I still remember very well how upset I was, when my mother explained to me what Sinead O'Connor's 'Nothing Compares 2 U' is about. The song, about the sadness of an abandoned lover, was a hit in February of 1990; I was five years old back then. I also remember my mother asking me why I was crying, and fibbing about bumping into the table. It was probably the least credible lie ever, but nonetheless it was a reflection of my Theory of Mind. After all, I *was* trying to trick my mother.

To this day I can get overwhelmed by other people's emotions at the silliest, most unexpected moments- during a visit to "Plopsaland" (a children's theme park in Belgium) for example. My ex mark and I went there for my twenty-sixth birthday, because K3 was to perform there. Together we had been watching the tv show in which the kiddie pop band went looking for a replacement for band member Kathleen, and we wanted to see how winner Josje would do live. While devouring a pizza, long before the gig was supposed to start, the music suddenly turned on. K3 appeared on stage. All kids jumped up, eyes widened to the size of dinner plates. 'Relax, sit down, it's just a little soundcheck!', Karen shouted into her mic. And me? I was crying.

Before you think I'm an obsessed K3 fan, and *that's* the reason I burst into tears: It wasn't. It was the children's' emotion, as they were suddenly surprised by their idols. It was the music. It was the whole picture, that was so overwhelming it suddenly made me emotional. By that time Mark was used to me a bit, but I myself found it quite embarrassing. I hunched over my pizza, pulled my cap a little further down over my eyes and pretended everything was fine.

And that's often what I do. Close myself off. Turn away. I refused to come along to *Soldaat van Oranje*, not because I hate musicals, but because I didn't want to be confronted with the emotions. I dread auntie Bep's birthday,

because I know I'll be overcome by the three big kisses, the loud laughter and the smell of gallons of old lady's perfume.

All autistics I know, recognize this. We close ourselves off to stimuli, and then get blamed for not having any empathy. For not understanding auntie Bep's good intentions. But to what extent does auntie Bep understand us? To what extent does she accept that our way of processing stimuli is different from hers?

## Theory-theory

Ehm, Toeps, Theory of Mind-theory? Isn't that just saying the same thing twice? Yes indeed, and it doesn't look good either. But it is correct. 'Theory of Mind' is the name of the concept, the idea that people can form an image in their head (a *theory*) about someone else's thoughts (their *mind*). And that theory? That's about Baron-Cohen's theorem that autistics wouldn't be able to do that.

## A double empathy problem

In 2007 a silverback gorilla named Bokito escaped from Blijdorp Zoo in Rotterdam. He attacked a woman, who sustained hundreds of bites, various broken bones and a shattered hand. The woman had thought she had a special bond with the ape: he 'smiled' at her and made eye contact. That by making eye contact, she was provoking Bokito, never occurred to her. Not even after repeated warnings from the zoo's staff.

The misinterpretation of animal behavior is a well-known phenomenon. For example, owners often project their own feelings and thoughts onto their pets, making them say things such as 'my cat is really headstrong' or 'my dog felt guilty'. According to Damian Milton, researcher at the University of Kent, a similar difference also occurs between autistics and neurotypicals: the double empathy problem<sup>1</sup>.

People like to fill in thoughts and emotions for others. They do this based on their own experiences: 'After hearing such news I'd cry, so if you don't that means you feel less sadness.' Even though Milton's theory poses that the empathy problem works both ways (hence the word double), it's the neuro-typicals of this world who decide what is the desired 'normal' reaction to all sorts of events and emotions. It's the neuro-typicals that have the majority, and therefore decide how autism is regarded. As a person with autism I often feel forced to *switch code*, to switch between two different types of behavior: my own and that which is socially desirable.

When I was in Japan for the first time, I noticed that a lot of what I considered to be set rules and concepts, were different there. Looking people in the eye, polite? Absolutely not. A bit of noise in a place makes for a nice atmosphere? No, antisocial. Slurping noodles, gross? Not at all, it makes the noodles taste extra good! I realized what Milton also concluded in his research paper: the social reality is a construct, a set of rules that the players determine together.

That's also the core of the problem of Baron-Cohen and associates' Theory of Mind experiment, which recently received the necessary criticism. The experiment takes place in a social setting, created by and according to the standards of neurotypical people. By definition, that influences the results. Analysis of video recordings shows that the researchers don't pick up certain non-verbal signals that the autistic children give off<sup>2</sup>. This causes the children

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<sup>1</sup> Milton, Damian E.M. , 'On the ontological status of autism: the 'double empathy problem'', *Disability & Society*, 27:6, 883-887, 2012. DOI: 10.1080/09687599.2012.710008

<sup>2</sup> Korhonen, T., Dindar, K., Laitila, A. and Kärnä, E., 'The Sally-Anne test: and interactional analysis of a dyadic assessment.' *International Journal of Language & Communication Disorders*, 51: 685-702, 2016. DOI: 10.1111/1460-6984.12240

to doubt themselves and adjust their answers. Children with autism are often taught not to trust their own feelings, so I'm not surprised they say what the researcher appears to want to hear. The interpretation of the results is lathered with neurotypical assumptions as well. But a researcher who thinks that someone has a problem if he or she doesn't answer questions according to neurotypical standards, they themselves have a lack of interpretation, in my opinion.

Autistics among each other usually have far less communicational problems. We find each other online, recognize each other's struggles and talents and form friendships in which we don't have to wear masks, where it's okay not to go to someone's birthday and no one is shocked by blunt remarks. And even in these friendships I sometimes feel insecure. Insecure, because the neurotypical behavior has been so exhaustingly pounded into me, I sometimes honestly don't know who I am anymore.

## The Intense World theory (and why it is *the* shit)

The Theory of Mind Theory mainly focuses on differences in communication, from the neurotypical's point of view. Milton's double empathy problem gives an explanation for the difference in communication, but we still have quite some way to go. We have a different neurotype, a different way of processing information, but why? And how do you explain someone's love for trains, hypersensitivity to certain textures or aversion to bright light and loud noise? A more inclusive, more comprehensive explanation can be found in the Intense World theory, a theory that has been gaining more credence in the past few years. The founders of this theory, neuroscientists Henry and Kamila Markram, have a son with autism. Their findings resonate with what a lot of autistic people actually already know: the autistic brain is hyperactive.

According to the Markrams, more connections are being made in the autistic brain, and braincells respond more emphatically to each other. Stimuli enter more potently, thoughts run rampant quicker. In short: the world is extremely intense for people with autism.

That doesn't just explain autistic people's hypersensitivity, but also the apparent insensitivity and the limitations in social communication. We close up in the overwhelming storm of stimuli, like a computer that freezes when you give it ten different tasks at the same time. Then, our hyper fanatical brain makes sure we remember that scary, nasty experience very well, and will avoid it in the future.

Or, as the Markrams explain in their scientific publication from 2010:

*'The intense world that the autistic person faces could also easily become aversive if the amygdala and related emotional areas are significantly affected with local hyper-functionality. The lack of social interaction in autism may therefore not be because of deficits in the ability to process social and emotional cues, but because a sub-set of cues are overly intense, compulsively attended to, excessively processed and remembered with frightening clarity and intensity. Typical autistic symptoms, such as averted eye gaze, social withdrawal, and lack of communication, may be explained by an initial over-awareness of sensory and social fragments of the environment, which may be so intense, that avoidance is the only refuge.'*<sup>3</sup>

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<sup>3</sup> Markram, K. and Markram, H., 'The Intense World Theory – A Unifying Theory of the Neurobiology of Autism', *Frontiers in Human Neuroscience*, 4, 2010. DOI: 10.3389/fnhum.2010.00224.

An abundance of stimuli can be tricky, but there's an upside as well. People with autism tend to have a very good eye for detail and have a knack for logic. Where neurotypical brains usually choose the well-trodden paths (which are quicker, but therein also tend to reason from generalizations and preconceptions, autistic brains explore every little side street and country road. For this reason a relatively large number of autistics work in science and IT, among colleagues who may not be autistic, but do possess a lot of the same traits. The Markrams argue that more autistics could use their potential, if their environment would enable them to do so.

Instead of showering autistics with stimuli in order to 'make them learn how to cope', or drill them like soldiers, they argue for a calm, predictable environment for autistic children, so they don't close up as much or develop anxieties. This way they can develop the positive aspects of their amped-up brain.

In their own words:

*'Behavioural treatment according to the Intense World Theory is proposed to focus on filtering the extremes in the intensity of all sensory and emotional exposure as well as relaxation and progressive systematic desensitization to stimuli presentation. The probably most counter-intuitive suggestion that emerges from the Intense World Theory is to surround the child with a highly predictable and calm environment protected from abrupt sensory and emotional transients and surprises for the first years of life to prevent excessive sensory and emotion driven brain development.'*<sup>4</sup>

So, as it turns out the old Dutch saying of 'calmness, cleanliness and regularity' is not so silly after all.

Uta Firth, one of the scientists on team Theory of Mind, felt this new theory breathing down her neck and decided to make herself look like a complete fool once and for all. On spectrumnews.org, the website that calls itself 'the leading source of news and expert opinion' in the field of autism, she wrote:

*'Our particular concern regarding the intense world theory centers on drastic suggested treatments for individuals with autism, namely withdrawing stimulation during infancy. The Markrams do not merely hint at such*

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<sup>4</sup> Markram, K. and Markram, H., 'The Intense World Theory – A Unifying Theory of the Neurobiology of Autism', *Frontiers in Human Neuroscience*, 4, 2010. DOI: 10.3389/fnhum.2010.00224

*interventions, but explicitly spell them out. Yet if the theory is incorrect, these treatments could be damaging. As studies of Romanian orphans have strikingly shown, insufficient stimulation and impoverished neuronal input in early development are damaging to children's social, cognitive and emotional functioning.*<sup>5</sup>

Sure, Uta. A low-stimuli environment can to-tal-ly be compared to a Romanian orphanage. A tip for Uta: that was sarcasm. Just thought I'd clarify that, because for someone who calls themselves an expert on the Theory of Mind, she has a very poor understanding of what the Markrams mean.

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<sup>5</sup> Frith, Uta and Remington, Anna, 'Intense World Theory Raises Intense Worries', 2014.  
<https://www.spectrumnews.org/opinion/viewpoint/intense-world-theory-raises-intense-worries/>