

1. Intro

I was diagnosed as being on the autistic spectrum in the year 1999, then seventeen years old. I had always been rather odd and isolated, and getting the diagnosis was a great relief for me. I had an explanation for why I struggled so much with socialising, and in various other areas. With the diagnosis it all had a name, and I had something to fight against. I and my family had an understanding of what it was that held me back. One doesn't succeed at something without knowing what you're dealing with, after all.

Still, getting a diagnosis earlier in life would have done me a great deal of good. It would no doubt have saved me a lot of emotional distress, and perhaps made dealing with my autism easier for everyone. Autism, in its wide spectrum, was simply less known back then than it is today.

For two decades now I have constantly thought about autism and observed myself, learning to be willing to discuss it with the people in my life, both for the sake of getting advice and for being understood. So perhaps I have tended to forget that the details of this condition aren't public knowledge.

In January of 2017 I did a lecture about living with autism in a conference room in the University of Akureyri, and that summer a local newspaper interviewed me on the subject. Both times the reaction was the same: People loved it, especially those related to autistic kids, and people thanked me for providing a better understanding of this whole business.

It's never a bad feeling to do a bit of good in the world, and information like this would have been of great use to me and those around me back in the day. So the thought occurred to write a little booklet for people in general, and parents in particular.

When I got my diagnosis one could acquire SOME information about autism, but we still had to do quite a lot of simply feeling our way around for understanding. So my goal with this booklet is to provide just the information I could have done with in my youth.

I am not a neurologist or a psychologist, and I haven't interviewed others on the spectrum for the making of this booklet. I am not writing from a scientific viewpoint, nor do I mean to go through all of autism's various manifestations. All us weirdoes are different, after all. Just like people in general. I'm also not out to create a revolutionary masterpiece. As I have done in interviews and lectures to date I simply mean to describe my own experiences, and hope it's of use to someone.

I also find that this text is much shorter than I originally envisioned. But then I do prefer to keep communications short and to the point, and the worst thing one can do with text is to pad it.

Onwards:

2. Childhood

So. As already stated I wasn't diagnosed until my teens. Until then I was just the weird kid. To me people were always making an issue out of things I didn't understand, or finding me odd, when to me I was simply logical and everyone else reacted strangely.

As a kid I was considered eccentric, and maybe sometimes in a cute way, such as my precise, "professor" like way of speaking. Some of the other stuff was less fun. I could display quite the temper, and I had a hard time making friends. I usually preferred to sit by myself somewhere and read. I was quite the voracious reader, and during summer vacations I took almost daily trips to the library, returned one bag of books and comics, and returned home with another bag. When I got a gaming console it started to slowly replace the reading.

But all of this was for a reason.

My mind is structured a bit differently. One scientific explanation of autism I've heard is along the line that certain parts of the brain don't develop fully, and so other parts overdevelop. My thought process can perhaps be compared to train tracks: Everything is based on logic and certain laws, and there is a need to take turns slowly and carefully.

One still shouldn't read too much into this simile. I am not a robot. I have emotions like everyone else. I just have a strong need for order, and for understanding what's going on. But human emotion, and human behaviour, are only partially based on reason. And when a kid is in a situation that is *wrong* in a way no one else understands, and incomprehensible factors hit him harder than he can handle, he quickly gets quite irate.

In the world of books I could find peace. As I'll cover later I can't intentionally shut out input, but I can get lost in something that interests me. I had little in common with the other kids, with their noise and boring ball games. My lack of understanding of other people, and their lack of understanding of *me*, did not go well with my sensitivity to noise. I don't know whether my lack of interest in ball games and such is a direct result of this, but either way I only knew I didn't get along with other kids, and had little I could do with them. Much as with the ball games I don't know whether shyness sprang from constant social mishaps or whether it simply played into it, but for the longest time I was severely lacking in confidence. I am of the opinion that about half our self-image comes from other people, and social isolation is far from healthy.

Clumsiness is a common physical symptom. I don't know the science behind that either, but somehow it's like my body isn't entirely under control. Fine movements are no problem, but when it comes to coordination and balance and such it's like the connection between brain and limbs isn't quite 100 percent. For the longest time I would walk so harshly that it was bad for my knees. I have managed to fix this a bit, but I tend to need to focus in order to walk without dragging my feet and

wearing out my shoes. I *think* that I need to step softly, but though I'm physically capable of it it just doesn't happen.

I never learned to skate, needed a long time to learn to ride a bike, and was utterly hopeless on skis. I loathed school ski trips. I hated being ordered into mandatory "fun" I sucked at, and hated being told by the teachers to not be so surly, and that I could totally do this if I just tried. Looking back I feel my childhood was much like having a limp but being told to maintain pace with everyone else.

"What's the deal? Just walk faster!"

It was the same way with mandatory dance classes, which led to a mandatory show. A boy with terrible coordination is obviously not a natural dancer, and much as with the skis I just found the whole affair degrading. This was before I got the diagnosis and my self-image was quite low, so the only explanation I had for my own performance was that I just simply sucked. And this isn't something I see with different eyes in hindsight. I still get a bit angry thinking about it, especially given that dancing damn well has nothing to do with preparing young people for life and further studies. I have quite a strong intolerance for the various kinds of pointless, avoidable bother people and society create, which is one reason why prejudice angers me as strongly as it does. It annoys me terribly when human existence is made more difficult than there's any need for it to be by nonsense like "tradition".

When someone brought up my solitude and expressed concern I usually reacted by shaking my head."

"What? Can't one just be alone?"

This was never looked into any further. But looking back I feel that I did in fact want playmates, but had somewhat give up; the kids didn't share my interests, I didn't know how to communicate, and so just wanted to read a book in my room, where I was free from noise and wasn't constantly getting into conflicts. With no understanding of what was wrong or how to tackle it I largely stopped trying.

3. Communication

One of the primary reasons for my social difficulties is that I wasn't born with the same manual as others. Most people automatically learn to read others and understand their feelings and behaviour, perhaps similarly to how a small child slowly gets better at talking.

But with me there is some sort of blockage.

It is not natural to me to understand what another person is thinking, or to put another's emotions into context. This can seem like a lack of consideration, but the fact is that I simply didn't understand why some things were appropriate to say and others were not, or why people didn't want me blowing my nose in the kitchen, and so on.

If someone tried to communicate something to me through implication it would usually fly right over my head, and I found the practice quite odd. I still do, really. To me communication is about delivering something clearly and precisely, which probably explains my childhood speech patterns. So when talking to an autistic individual, don't imply; *state*. And encourage the person to do the same. I didn't always understand that others didn't get me any better than I got them. To me my reactions and thought patterns were, after all, perfectly reasonable.

This does have other manifestations. It is only in recent years that I've come to understand how appearance and presentation effects people. I worked in a large store for a while, and I was reluctant to accept that it made any difference how the products were laid out. The way an employee has set up a duvet has no effect on its quality, after all. That is how my worldview was, and in some ways still is: Simple two-plus-two logic.

I also gave very little thought to the clothes I wore, and what the state of my apartment was when I received visitors. And I still sigh when mom complains about my couch having gotten rather ugly. It's exactly as comfortable as ever, and so I'm in no hurry to replace it.

And if I may get up on my high horse for a moment, I feel there is a validity to this attitude to life. But I would say that these days I'm perhaps halfway in between a regular outlook and my old one. And I don't know if I'll ever move beyond that.

But as I said before, I didn't get the human manual. My experience is that an autistic kid has a very limited ability to put themselves in someone else's shoes. It would perhaps be fair to say that it just doesn't quite occur to them. My ability to read people's emotions was limited, and I didn't necessarily realise they didn't share my interest in a subject. So I had a tendency to talk and talk about stuff no one wanted to hear about, or be intrusive, insult people through bluntness, or take harmless joking very personally.

I do want to stress that not *understanding* someone's feelings is very, very different from not *caring*. When I realised that I could be annoying I got very sad. And as I gradually improved in

understanding myself and others fear of this tended to hold me back. But I didn't want to be a bother, and kept to myself. I still have a poor sense of how people feel about me, and have a habit of assuming the worst.

But I want to repeat myself, because this is a misconception that annoys me terribly: A lack of UNDERSTANDING is not the same as a lack of SYMPATHY. An autistic person just senses the world in a different way. All it takes is clearly explaining causality: "I feel A when you B, because C."

So, clear and plain communication is very important when dealing with an autistic kid. And though I'm using metaphors in this text I advise against them. No few arguments in my teens went completely off the rails when a parent or someone else was talking about A and used B as an example, and my first reaction was to point out a flaw in the comparison. This wasn't done to muddy the waters. This is just how my mind works. Correct is correct.

But though I still find myself unsure of what is appropriate to say in a situation I have improved a great deal over time.

4. Input issues

Though I've won many victories in my efforts to learn to live with myself sensory input gives me trouble to this day, and is probably my biggest problem.

I somehow don't have the same filter in my head as other people. I lack the ability to shut out input, and in particular sounds. All sounds around me just flood in and can greatly wear me down. If I'm downtown at a festival or at a big party or some such I'm faced with terrible, non-stop clatter that soon becomes unbearable.

One of my personal theories about autism is that an autistic child will early on withdraw within themselves as a reaction to all that damn input; that some of the symptoms are quite simply an instinctive reaction one needs in order to cope.

This can perhaps be compared to friction. It may be perfectly fine at first if something is rubbing against a person's skin. But if the rubbing just keeps on going it starts to hurt, and eventually it will have dug its way through and is scraping against exposed nerves.

No one would expect someone in that situation to keep their cool. Obviously a person will howl with pain as their skin is being scraped off. But an autistic kid who throws a fit won't necessarily meet with the same understanding.

But it isn't exactly pain. Noise doesn't trigger my nerve endings in the same way a cut does, but I just can't think of any better description of how I feel when this effect is at its worst. When I'm tired and my defences are down a simple sound like lip smacking or cutlery being used will flat-out hurt me, in a way I can't properly explain so someone with a typical nervous system. This is one of the things that make communications and "normal" life so difficult. I am especially vulnerable to certain sounds, particularly shrill ones, and I have a hard time being around people with high voices. But it doesn't take extreme examples to aggravate me.

In the summer of 2017 my father was visiting the country. One day we decided to take a day trip around a peninsula. We set off in the morning, visited several locations along the way, and came back home shortly before dinner. There is of course a limit to the stimuli one is exposed to inside a car. I wasn't in a mass of people, and no one was screaming in my ear. Nevertheless I was utterly exhausted as I got home. I had to lie down for a while before having dinner, and I was more sensitive than I'd been in a long time.

The issue wasn't that something dramatic had taxed me during the trip, or that I can't appreciate a nice view or spending time with dear old dad. The issue was simply that I'd experiences minor stimulus for hours on end without the option of getting away and recharging my batteries. Company simply taxes me, and this sensitivity is the reason I don't think I could ever cohabit with another human being. I have a great need for being able to control my environment; to have one place on

the planet where I can be safe from input. Unfortunately this means that travelling is a certain risk. I do enjoy seeing new and interesting locations, but far from home, in circumstances I can't control or get away from, I'm at risk of turning into a wreck, unable to enjoy the trip.

My vulnerability to this effect varies greatly. Sometimes it is exacerbated by fatigue, or stress or some other internal issue, and sometimes I simply can't explain it. If pressed to point out some cause I'll say that I've noticed that I can get "rusty" at tolerating input if I've been isolated at home for a while.

I want to stress that this can make an autistic person highly sensitive to touch. Much as with my tolerance in general it depends on my mood, but I highly dislike it when people touch me by surprise, *especially* when I'm absorbed in something. When I worked in a supermarket during busy hours I loathed it when customers walked up behind me and put a hand on my shoulder.

For years I made the mistake of trying to be like everybody else, and before I figured this whole thing out I tried to force myself to stay in crowd situations. But all it did was infuriate me. I have learned the art of just making brief stops. Sometimes I'll go aside and take a break from the noise. I take a few breaths, and even cover my ears and close my eyes to regain some of my energy. I'm also very reluctant to accept a ride to something going on outside of town. I need to be able to control when I go back home, and so I want to use my own car.

I would urge parents with a kid in such circumstances to just pay close attention and ask if s/he wants to take a break. Feelings can't necessarily be seen from the outside, after all, until they boil over.

There is of course a limit to how much quiet one can seek out while travelling, but it's worth keeping all this in mind.

5. Thought

To get back to the matter of train tracks and turns, I have a certain need for predictability. It relates to my need for order, and things being “correct”, which may be one of the main issues in all of this. I tend to ask quite a lot of questions about events, trips and such beforehand, and unexpected changes tend to put me on edge. If I was invited to a family trip or a visit or some such my immediate reaction was to say no. But after the chance had passed and I sat by myself at home I started to realise that of course it would have been more interesting to go along. I have improved at this, as with so many other things, but still occasionally fall into that old instinct to stick to the plan. Even if the “plan” is nothing more interesting than browsing through Youtube.

Of course there are plenty of more interesting things out there in the world, but this is the way everything initially hits a certain wall. I need to digest a development. Mom eventually figured this out when I was a kid, and was mindful to suggest any outings ahead of time.

Now that I’m on my own I try to keep this process in mind when something unexpected comes along. I try to coldly and analytically decide which option will do me the most good. What it is that matters more to me and brings me more satisfaction.

Another example of this is that mom was fond of rearranging furniture, and it always greatly annoyed me. My autism is overall rather mild, and I can well imagine that a kid with a more severe case will take such changes *really* poorly. So my advice to parents is to mention all coming changes in the home well ahead of time. It’s no guarantee that the kid will take the changes well, but hopefully at least *better*.

Not that long ago I witnessed this from the outside. I made a last-moment decision to join a friend for mine for a movie. I called him, by which time he was already at the cinema and offered to fetch me. When he arrived someone else was at the wheel, and was very visibly irate over having to make a detour shortly before the movie. Though I was meeting this man for the first time I found the symptoms quite familiar.

He drove me and my friend to the theatre a few minutes before the showing, but then just hurried home, too surly watch a film. My friend admitted that he should have expected this reaction.

Though I’m not quite this extreme, at least not these days, I understood the man just fine. From a logical perspective nothing had changed; there were plenty of tickets left and the movie itself certainly didn’t change due to the car drive. But things had been taken off the rails, and he couldn’t redirect himself in time to want anything to do with any of it.

But this whole train track business has other manifestations. No one *likes* being interrupted when they’re busy with something, but I think irritation over this is particularly potent in me. I want to do *one* thing at a time, and finish it before something else demands my attention. I strongly dislike it

when someone cuts me off in a conversation, and I get very irate very quickly if someone does it multiple times in a row. It unbalances me terribly.

When I worked in the supermarket, on my way to some task, and someone bumped into me, I much preferred it when they just stayed silent rather than apologise. When I'm focusing on something I can shrug off discomfort, but words demand thought and attention, and I prefer to stick to a subject.

This next part is stepping outside of my area a little bit, because as I said I'm not a psychologist, but though I'm not one of those non-verbal autistics I think I understand them. I suspect it has to do with the train tracks. I just happen to be more adept at rerailing. I think the silent ones are simply like me when I am at my worst, and most inside of myself. I sometimes enter a state where I'm terribly closed, I've gone way inside for the sake of some peace, and I strongly dislike having to speak. I *can*, but it clashes with some strange need I can't quite explain.

Rationality is a very important cornerstone of my mind. Humans certainly are creatures of thought, but also of emotion. And though I certainly have emotions I think my *understanding* of things is more based on plain reason than is typical. One might perhaps say that my thoughts travel in a straighter path than with most people, free of the rainbow of interpretation, baggage and complexities people create.

This, coupled with my lack of understanding, is why I spoke bluntly about anything to anyone. I never sugar coated anything. Lying goes directly against my nature. And let me be clear that I am not claiming some kind of moral superiority. It was just absurd to me to twist facts, or claim that things were different from how they really were.

I honestly still do feel this way, and it still bothers me how much human society requires all sorts of insincerity, and how many irrational problems humanity creates for itself, such as short-sighted environmental policies or prejudice. But it is also a logical fact that I can't turn the entire human race over to my opinion, and so I've learned to reach across the isle. At least a little.

6. Progress

As I have mentioned several times in this text I have made great gains. And what I want to state more clearly than anything else in this booklet is this:

A person in my position can manage.

No, I don't walk entirely the same path in life as a "normal" person. No, I will never *stop* being autistic. Yes, I meet with certain obstacles "typical" people don't need to deal with. But so what?

There is no *correct* way to live one's life. My life belongs myself and no one else, and I have broken the bad habit of being angry with myself for not fitting the box society wants to place people in.

It's perfectly okay to not want to participate in a big festival, or be more interested in a book than watching grown men kick a piece of leather between themselves.

My life is not perfect, but no life is. One thing I have learned over the years is that there is no finish line one needs to cross, after which you've won at life. Every period of life brings new challenges.

These changes that have improved my life so greatly are born of my will to learn. No, I don't have the user's manual. Learning all those little things isn't *natural* to me. But I possess full intelligence, and that is my saving grace. Since I got the diagnosis I have always been on guard against my pride, and worked to be willing to consider whether I'm behaving correctly or not. I've also been blessed with loved ones who took my diagnosis with understanding, and we agreed they would offer advice and point out my mistakes.

These relationships have been of tremendous help to me, and probably have had much to say in how I'm doing today. But such relationships of course need to work in both directions. Friends and family need to pay attention and give constructive advice rather than scold, and an autistic person needs to be willing take criticism under consideration.