

Autism From The Inside

A personal perspective on the issues faced by autistic adults in everyday life

“Before you judge a person, walk a mile in their shoes.” If only it were always that easy! Not everything in life is as easy to change as our footwear, and not everything is as straightforward to experience as different options for what we wear on our feet. What can be most challenging of all is understanding why others think in a different way to us and come to very different conclusions from ourselves from the same evidence.

Different ways of thinking can arise from many causes – genes, upbringing, influences of others, the impact of traumatic events and so on. This is then coupled with the fact that each one of us is different and totally unique, so of course we have different thoughts.

For some of us, there is one very clear reason why we see the world differently. In the UK, it is estimated that around one in a hundred people are autistic, though they may not all know that they are. As I did for most of my 50 years, they may well know that they are different and wonder why life seems so hard and so strange without understanding why. Even when you know that someone is autistic, it can be extremely difficult to see how they can possibly perceive the world in such a different way.

Like everyone else, all autistic people are different, and our autism affects us all in different ways. There are, however, some common traits that are experienced by many autistic people. Since you cannot learn how it feels to be autistic by wearing my shoes – all that will tell you is that I have big feet and poor taste in footwear – the purpose of this piece is to try and describe how I see and experience the world as an autistic adult with a full time job. Wherever you live and whatever you do, you will know somebody with autism at some point in your life, and a little understanding can go a long way.

Strangers in a strange land

In simple terms, the world is designed to suit the needs and behaviours of neuro-typical people (known as NTs, the phrase used to describe those who are not neuro-diverse). The world in general takes no account of the fact that many autistic and other neuro-diverse people can be easily over stimulated by any or all of their senses and can rapidly become overwhelmed.

For me, the biggest issue is noise. A small room filled with people all talking at once is an absolute nightmare, as my autism means that I cannot filter out any of the other conversations to focus on the one I am part of. I cannot help myself from trying to listen and comprehend every single voice that I can hear the whole time. Since the human brain is not equipped to listen to several things properly at once, I quickly become overloaded and overwhelmed. I reach the point where my only option is to leave that environment to avoid breaking down into tears as I simply cannot cope any longer.

For other autistic people it is one or more of the other senses. Offices filled with white furniture and white walls may look beautiful from an interior design perspective, but they can be hugely overstimulating for some. Others can find strong smells completely overwhelming rather than the minor annoyance they may be to the rest of us.

We live in a world designed to bombard our senses, to compete for our attention. For many autistic people, this is exactly the opposite to what they need. We are simply not designed to cope with or thrive in such an environment. While I would never advocate or suggest that everything should be changed for the benefit of autistic people, there is surely more room for compromise than we see at present.

The changes are coming. Shops are offering quieter periods for autistic people, areas with reduced stimulation from the environment are being introduced. But in some cases are the benefits of the things that cause the problems for autistic people worth the benefits to others? In my experience, large open plan office spaces which are difficult for myself and other autistic people are not well liked by many NT people either. Of course there are always arguments on both sides. I like places to look nice as much as anyone else. But then staircases can look beautiful, and we at least now recognise that stairs as the only way of accessing a public space is no longer accessible for very good reasons.

Reading the signs

It's good to talk. It really is. But we are fortunate to live in a world where there are many different ways of talking. For many autistic people, face to face communication, or even any other form of verbal communication particularly with people we are not totally comfortable with, and especially complete strangers, is extremely stressful. Many of the key factors that form part of spoken communication make no sense to lots of us. I find it incredibly hard to maintain eye contact when speaking to others, and yet I am frequently told how disrespectful it is not to do so. All my life I have been criticised for my poor body language and for misreading the body language and tone of others. My answer has always been to listen to the words I am actually saying, not the tone you think I am intentionally using, or how I am standing or sitting when speaking. I get that these things make a huge difference to many people and that body language and tone can tell you a huge amount, but I cannot interpret these signals nor properly control those that I give out. Please say what exactly what you mean to me rather than saying one thing while meaning another – I just won't get it.

For many autistic people, therefore, the internet and other electronic communications are a huge positive. There is no body language or tone of voice in an email or text message. Yes, words can carry a tone but that is easier for many of us to check and work out. And actually, would it really be such a bad thing if we all chose our words with a little more care and thought?

Behind the mask

When you live in a world not set up for you, you have two choices. You can either fight everything all the time, or you can try to fit in by pretending to be somebody else. While fighting everything all the time has a certain appeal to me and some who know me may say that is what I do, it is really not an option. We all have to pick our fights and take time out to heal and recharge. While I would definitely advocate us all fighting a little more and with a little more passion for the things that really matter, full time fighting is just not practical. Sometimes we all feel a need to just try and go with the flow, to fit in, to not stand out from the crowd.

Many autistic people are acutely aware that we are different and seen to be different. Much of the time I am proud and happy to be the weirdo geek in the corner, but not always. And when we want to fit in with the world, the only way for us to do so is to put on a mask.

I don't get small talk. I don't understand what it is for, what it is supposed to achieve or how it works. Most of all, when in a "small talk situation" I have absolutely no idea what to say. So many times I have sat through incredibly awkward silences as I simply cannot think of a single topic for conversation. It is embarrassing for all concerned. I could give a myriad more examples where I have to try and pretend to be somebody else in order to fit in, to not come across as strange as far as the world is concerned.

Whether this act is successful or not I am not sure – probably not for most of the time. But I do know that it is absolutely exhausting. The things that many people do automatically without thought require a huge effort, taking up a large proportion of the energy I have available. This in turn makes me more tired and like many I cannot help becoming a little less tolerant when I am tired and a vicious circle continues.

Many autistic people are very tired a lot of the time, both because they have to spend much of their lives pretending to be people that they are not, and also because many autistic people also suffer from mental illness. I have severe depression and anxiety. I am in no way qualified to make any direct connection between my autism and these conditions, but I do know that living in a strange world and having to play a game that I do not understand with no clear rules in no way helps.

The box

And yet despite all these difficulties, and I really do wish they could be addressed as some of the solutions seem so clear and easy to implement if the understanding and will to do so were there, I am glad I am autistic, most of the time at least. That is who I am. A non-autistic Mark would not be me, it would be a different person. I don't know how to be anybody else despite a lifetime of pretending most of the time.

Most of all I love that I think differently from many others. Of course it is a pain when I continually miss the apparently very obvious, but the joy of finding solutions and approaches not otherwise considered is tremendous. Autistic people don't think outside the box – we don't actually know or understand what the box is. Whatever it is, we probably don't belong in it anyway.

We all have aspects of our selves that make us unique and we should celebrate these. I am glad that I am me, but one of me is more than enough for the world!

The future

This piece is not intended to be a moan or a rant, and apologies if it has come across as such. Things are definitely improving for autistic people in some areas of life at least. But the key to progress in all areas of our lives is understanding. If I can play even a small part in that, I am grateful.