

Imagine having Autism

In recent years many adults with high functioning Autism Spectrum Disorder (ASD, often referred to as Asperger's Syndrome) have written and spoken about their experiences and feelings. These works have given the neurotypical population an insight into how children and adults with ASD experience the world around them. This increased understanding has led to more successful management techniques.

The major diagnostic areas of impairment in ASD are social communication and restricted, repetitive behaviour or interests, but I think these are secondary to the impairment of imagination. The "Theory of Mind Deficit" of Autism proposes that a person with little or no imagination would find it difficult to understand and interpret what another person might be thinking.

How does our imagination dictate our day-to-day thinking processes? We have an 'imagination factory' inside our heads, used often without us really being conscious of it. As we observe someone else's behaviour we are very quick to guess or imagine why they are behaving in that way. We cannot 'read their mind', but we are very good at imagining what they may be thinking in order for them to behave in that way. An example is when we see someone waving to us. Do we ask why she is shaking her hand in the air? No, we make an instant guess – she wants to communicate with me. We are equally as quick to dismiss other possibilities, like the possibility that she is shooing flies, based on our instant judgement.

Another example of our everyday use of imagination is in conversation. As someone is speaking, we make constant use of our imagination – "why are they saying that and what can I say to join in the dialogue, and what will they think if I say that?"

Children's pretend play is an important part of the development of imagination. Young children frequently pretend, or imagine, that one object, such as a banana, can be used as another object, such as a telephone. Children with ASD find pretend play very difficult – they tend to engage in reality play by copying what they see around them – the other children or their favourite video. The lack of pretend or imaginative play is a key diagnostic tool – the young child with ASD is rarely capable of spontaneous, creative, flexible play.

What is it like to not have the imagination skills to be able to instinctively guess what is going on in someone else's head? An adult with ASD has reported that he is exhausted by the end of the day from the time and effort required to 'compute' everything to help him decide what to say, do and think. Because it takes him time to work out how to respond, he is easily misunderstood by others, thus compounding his confusion. By the end of the day when he returns home he is exhausted and this is often reflected in his behaviour. Being in crowds with people behaving differently is a further complication. Most people with ASD dislike groups of people – sometimes they get excited but don't know how to engage with the group; other times they can withdraw, or become angry, or panic.

To understand a little of what it must be like, picture those times you have tried to come into a conversation half way through. It takes time to work out what is going on and when, or if, it would be appropriate to enter the conversation.

Many people with ASD report experiencing frequent panic attacks. One person has talked about living from minute to minute because he is unable to anticipate or guess what is likely to happen next. When his tram for work is late, he has a panic attack because he is unable to 'imagine' how he will be able to get to work. To be able to predict what may happen later on, the next day or next year is extremely difficult.

Many people with ASD develop rigid structures or routines in their lives. We now understand that they do this, consciously or unconsciously, to help them manage the chaos they experience. People with ASD have reported that if most events happen in a predictable sequence, they have more energy available to manage the unpredictable. Even then, assistance, often in the form of visual prompts or rehearsed 'scripts', is often needed – a card in the pocket prompting to get a taxi if the tram is more than 10 minutes late, or a script (such as a Social Story) outlining the routine if a teacher is absent – these are important strategies to develop.

Everyone experiences anxiety, some more than others. So too for people with ASD. This goes some way in accounting for the variation we have observed along the Autism spectrum. The more anxious a person with ASD is, the more rituals and routines they are likely to develop. Lower functioning children with little or no capacity for imagination have a great need for rigid and inflexible routines, as well as stereotypical behaviours such as hand flapping and rocking. At the higher functioning end of the spectrum, the person with more imagination may have a decreased dependence on routines and rituals once they become familiar with a situation or environment.

Parenting the child with ASD is made more difficult by their imagination deficits. How many parents have felt that punishment seems to make no difference to correcting 'naughty' behaviour? Children with ASD are often judged to be manipulative or behaving badly on purpose. For a child with little or no imagination this is almost impossible. To manipulate or purposely distress a parent requires the child to imagine what his or her parent is thinking and to try to change those thoughts to their advantage. 'Naughty' behaviour usually reflects the child's difficulty in understanding what is going on around them – their behaviour is a reflection of their increased anxiety and confusion and routine punishments only make them more distressed. In fact, time out is often just what they want (and need) – a quiet space with no 'people' demands!

We ask huge things of children with ASD. We send them into adverse environments that are full of people and noise, such as schools and shopping centres. We demand social interaction. We want them to join in conversations. We want them to play happily with other children. We often require them to give up a ritual, routine or obsession which has been helping them to reduce their anxiety. We send them from the structured classroom to the unstructured playground "for a break". Children with ASD have to work even harder in the playground – to make sense of the countless unwritten rules for social interaction. Recess is no break unless a structured, predictable recreation routine is developed to support the child with ASD. This can and should include a small group of peers who understand the child and have been taught how to respond positively. A child with ASD at a school that has set up a small PlayStation room, where one peer per break is allowed to share the activity, has gone from being the bullied outcast to the most popular child in the class!

It is important that everyone – parents, extended family, teachers and friends – understand that children and adults with ASD are not like neurotypical people. They do not think in the same way and they should not be treated like everyone else. Choose recreation activities carefully – team games like football or basketball are not overly successful, but individual activities such as tennis, golf, tenpin bowling or chess are more so. Computers, video games and the internet are much enjoyed by many people with ASD. Careful guidance can ensure they become shared activities in a number of ways – via interactive and shared games and programs, chat rooms and special interest clubs. Make allowances for the enormous effort they put into getting through each day – is homework more important than time to recover from a highly stressful day?

Try to imagine what it is like for the person with ASD to live in our world.

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