Life as an 'Aspie'

Val Carlin looks at the facts behind Asperger's Syndrome

Asperger's Syndrome is part of the broad spectrum of Autism. People on this spectrum see the world differently and can appear socially awkward or eccentric. As it is a spectrum, individuals have different combinations of traits and experience them at differing intensities. Many Aspies are high-functioning, particularly in their area of expertise, but socially isolated and therefore apt to suffer emotional problems. As their intellects help them to compensate, many higher-functioning Aspies remain undiagnosed or are only diagnosed later in life.

Asperger's Traits

Communication difficulties. Aspies can be very articulate and not even aware that they have Asperger's. They often have a high level of vocabulary and formal speech patterns. They can be overly precise in what they say, state opinions as fact and disagree over minor details. For Aspies, accuracy can be very important. They take comments literally, often misunderstanding jokes or colloquial expressions, and have difficulty understanding the unwritten rules of conversation. They say exactly what they mean and don't pick up on indirect comments or implicit double meanings.

Relationship difficulties. Aspies usually want to develop relationships and be included in society, but are hampered by their communication difficulties. They often don't look at people's eyes, making it difficult to notice or read facial expressions. They often remain unaware that they have said something inappropriate and will carry on talking when the other person is annoyed or not interested. They can also disagree vehemently, as they don't understand that people might be upset by such disagreement.

Lack of imagination and creative play. Aspies may lack imagination and find creative play or thinking in the abstract very difficult, as their brains process information differently. They are particularly good at learning facts and figures and may have extraordinary powers of concentration or memory. They are more prone to developing obsessional interests and will talk about them incessantly to the exclusion of all else.

Often Aspies want to know everything about their chosen topic of interest and become expert in their field.

Routines and systems. Some Aspies need stable systems and patterns; they can become extremely anxious if their routine is disturbed. Like most Aspie characteristics, this isn't true of everybody and a lot of Aspies love travelling, finding it easy to adapt to the change of routine.

Sensory Sensitivity. Some Aspies experience sensory overload and can be very sensitive to noise or light. They often don't like being touched and will buy clothes on their feel, not their looks. Working in loud, crowded places would be unpleasant for a lot of Aspies.

However, in the right environment – quiet, with no flickering lights – they are capable of working alone for long periods of time. Although many Aspies can make eye contact when listening, most cannot look at people's eyes while talking.

Asperger's and Autism: the difference

Asperger's is one of the five Pervasive Developmental Disorders on the autistic spectrum. As defined by the Autism Society Of America (ASA): "Both children and adults with Autism typically show difficulties in verbal and non-verbal communication, social interactions and leisure or play activities". Though the broad definition is the same, these traits are more pronounced in Autism.

> *"In my experience, 'Aspies' and Mensans seem to have a lot in common... both groups tend to like debate..."*

They are also joined by symptoms such as a lack of language, inappropriate attachments to objects, very inappropriate emotional displays, repetitive movements, no fear of danger and over- or under-sensitivity to pain. Those with Asperger's Syndrome are usually of average or above average intelligence, according to the UK's Asperger's Syndrome Foundation. Therefore, while Asperger's often goes undiagnosed, Autism typically becomes obvious during the first three years of life.

Some people live quite happily without a formal diagnosis. However, there are a lot of people who feel the need for one and many who want help to "fit in" with society. I tried many times to get help for my social difficulties, but every professional person I turned to could never see the problem. They always insisted that I just suffered from low self-esteem, which is far from true!

Doctors' inability to recognise Asperger's seems to be a frequent problem for higher-functioning Aspies, especially female ones. According to The Sunday Times (February 6, 2010) autism and related conditions are being under-diagnosed in women and teenage girls. Females are usually better at masking the symptoms, such as difficulties with language, and better able to compensate for their problems. However, non-diagnosis can lead to a life of preventable isolation, low self-esteem and even suicide.

At the moment, it is very difficult for a high-functioning adult to get a diagnosis. One criterion often used for refusing a diagnostic test is having an IQ above 70. Yet one of the criteria for Aspies is an IQ of normal or above!

However, things are changing. In December 2010, the Government published statutory guidance for local authorities, setting out the legal obligation to ensure they meet the needs of people on the autistic spectrum in England. It states that people can no longer be denied an assessment solely based on their IQ and that there must be a clear pathway to diagnosis. This is due to come into force in 2013.

Scientific Research

Professor Simon Baron-Cohen, Director of the Autism Research Centre (ARC) at the University of Cambridge, led a recent study into Autism. It showed that Aspies are more likely to become accountants, engineers, IT professionals or history professors than artists, DJs or social workers.(See http://www.autismresearchcentre.com/docs/news/2011_Roelfsema_Eindhoven%20press%20release.pdf)

Baron-Cohen has also designed an on-line diagnostic test to give an indicator of autistic characteristics. It cannot replace actual diagnosis by a suitably qualified person, but it can give an idea and raise awareness. Accurate diagnosis must take into account the number, pattern and intensity of the traits in an individual. This potential for variety makes Asperger's a spectrum rather than a simple yes/no.

It can be found here: http://www.wired.com/wired/archive/9.12/aqtest.html

A Facebook page for Aspie Mensans and their families

There is very little, if any, help currently available for higher-functioning Aspies. While I was trying to develop my sales and marketing skills, I came across Neuro Linguistic Programming. It helps in understanding people's behaviour and breaks down communication into easily-learnt steps. I found free two-day courses running every couple of weeks in London, so I booked on one – nothing ventured and all that. I found the NLP course to be more helpful than the Asperger's-specific courses currently available.

I am in the process of setting up a similar course especially for higher-functioning adults on the autistic spectrum. I have also set up a Facebook page for Aspie Mensans and ex-Mensans, their families, friends and any high-functioning people who experience social difficulties.

This is a self-help group to facilitate communication, share ideas and promote social skills. If anybody would like details, please contact me on valcarlin@hotmail.com

Aspie Issues

Unfortunately, their communication problems can cause Aspies to come across as opinionated, insensitive, rude or self-centred. Aspies are fine with factual conversations, but not so good at chit-chat. Often, I give a very good first impression and people instantly warm to me. However, over time, I found that I antagonised people and I could never understand why. People would frequently tell me I was tactless or didn't listen and that I should think before I spoke. While I could accept that was true, I needed more specific examples of what was tactless or why people thought I didn't listen. They may have been well-meaning, but I didn't find it helpful. I really didn't know what was tactless and no amount of thinking about it helped me to realise.



■ **GENIUS: Mozart is among many talented people believed to have suffered from Asperger's**

The Mensa Connection

From the age of 21, I was quite active in Mensa. I always found it strange that I seemed to be more accepted in Mensan society, but really struggled in "normal" society. At the time, I knew nothing of Asperger's; I was 40 when I discovered it. Since then, I find that around 40 per cent of Aspies I meet have joined Mensa at some point in their lives. While this isn't representative – as I only meet higher-functioning Aspies – I believe there is a high incidence within Mensa.

I also think a significant number of Aspie Mensans don't connect their own issues with Asperger's. They confuse it with Autism, although Asperger's is actually quite different, even though it is on the same scale.

However, discovering and addressing it allows for better self-awareness and the chance to develop social skills, improving both self-assurance and relationships.

In my experience, Mensans and Aspies seem to have a lot in common. Both groups tend to like debate and can quickly and easily go straight into deep conversations with minimal small talk. Disagreeing is perfectly acceptable, while decisions are likely to be based on information more than emotion.

Although non-Aspie Mensans may not have the same communication difficulties, they are (in my experience) more accepting than the general population. They seem to mind less when someone gives their opinions bluntly and are confident enough to disagree!

I started my professional life as a financial analyst. Although I was good at the actual job, people tended to exclude me socially, so it was difficult to progress in my career. Eventually, I retrained to be an independent financial advisor so that I could work for myself. I am CeMAP, CeFA and CeRER qualified. I specialise in helping families to protect their children financially should anything happen to the parents and in safeguarding single professionals' lifestyles in the event of illness. Because of my own experience, I have a particular interest in helping parents with disabled children to rest assured that, no matter what happens to them, their children will be financially secure when they have gone. (See http://www.facebook.com/valcarlin)

**This article was written by Val Carlin and edited by Rebecca Ridolfo*



True tales behind the Rain Man story

Islands of Genius: The Bountiful Mind of the Autistic, Acquired, and Sudden Savant, by Darold A. Treffert.

This book examines the minds of genius savants and calls for their talents and abilities to be nurtured and developed to help mankind.

Its author, Darold A. Treffert, is Clinical Professor of Psychiatry at the University of Wisconsin School of Medicine and has worked with savants and researched this rare condition for nearly 50 years.

He is probably best known, however, for his work as a consultant on the film Rain Man, in which Dustin Hoffman plays the part of an autistic savant.

Kim Peek - the inspiration for the film – is just one of the extraordinary individuals Dr. Treffert introduces us to in the book.

Savant syndrome is a rare condition in which individuals with developmental disorders, including autism spectrum disorders, have one or more areas of expertise, ability, or brilliance – "islands of genius" – that exist in contrast with their overall limitations.

Dr Treffert looks at new discoveries that raise interesting questions about the hidden brain potential within us all. He also explores the phenomena of genetic memory – instances in which individuals somehow "know" things they never learned – and sudden genius or "acquired savantism", where a neuro-typical person develops savant-like abilities following a head injury or stroke. Showing that these phenomena point convincingly towards a reservoir of untapped potential within us all, he looks both at how savant skills can be nurtured, and how they can help the person who has them, particularly if that person is on the autism spectrum.

Islands of Genius is published in the UK by Jessica Kingsley, priced £15.99.