Asperger Syndrome: One Prisoner's Experience

Ross Gordon, Lifer at Leyhill prison.

My background

I had what others describe as a traumatic childhood during which I was abused physically, emotionally and sexually. I had no understanding of what was going on and could make little sense of the world around me. I was told I was intelligent but I just did what I did because I was happy in my own world. I did not speak until I was about five years old or at least not the way others spoke. I had my own language and only my elder sister could understand it. She used to act as an interpreter for me, and my parents and teachers often had to call on her services. I could shut myself away in my own world for as long as I chose and during such periods it was as if nobody else existed. My memory was always very good in the sense that I could hear a conversation or watch a television programme or read a comic and weeks or months later could recall everything virtually word for word. It was not a conscious effort but now and again something would trigger me off and the words just seemed to come back. This led others to think I was intelligent and they had expectations of me, which I could not always live up to. I found it very difficult to make friends and could not communicate in social settings.

The world was just a mass of confusion, which I was trying to make sense of. I was very disruptive at school and home and I was frightened most of the time because I wanted to fit in and be normal but I also realised at a very early age that I was different from others. I had no idea what was wrong with me just that something was not right. I saw a speech therapist who taught me how to shape my mouth to make various sounds and I quickly learned to speak. However, this was awkward at first and other children laughed and bullied me until I learned to fight back. I also learned I could make friends by being disruptive and abusive to teachers and adults in general. As a result of this I saw a child psychologist who said I had Attention Deficit Disorder but none of the treatment seemed to work.

Almost inevitably I drank, took drugs and turned to a life of petty crime to finance my 'using'. I knew that life was much easier for me when I was drunk or stoned because it did not seem to matter that I was different and people blamed my 'using' for my lack in social and communication skills. This lifestyle led to me being given a life sentence for murder in 1977 when I

was eighteen years old. There were no tariffs in those days but the judge recommended I serve a minimum of ten years. Almost 25 years later I am still in prison.

Prison

Surviving in prison has not been easy. I had to force myself to maintain eye contact with people because I soon learned that lack of eye contact was seen as a weakness and I would become an easy target. I have trouble reading body language and take things literally. I often felt threatened for no reason. For instance, if I heard a con shouting out of the window at another con and he said 'I'll rip your head off in the morning' then I expected him to do it. I was always confused by such language and had to get used to it but this meant I never understood when my behaviour was genuinely upsetting people and I was putting myself in danger. It was very confusing for me trying to understand the difference between situations and my mind constantly worked overtime analysing every interaction in an effort to find some sort of pattern or structure to work to.

Interviews always confused me but I soon learned from the other cons what was being looked for and tried to behave appropriately. I was often misinterpreted as unemotional and never knew how to change this except by observing and mimicking others. Needless to say I got into trouble whenever I ventured out of my 'safe world' for any length of time but I realised I had to from time to time because staff were starting to call me antisocial. I could never explain how much I enjoyed 'bang-up' and how I found time in the block to be a much needed holiday. The isolation was heaven for me and I resented it if I was forced to go out on exercise for an hour. However, there was always a longing inside me to be normal and to have friends so I would plan how I was going to make things work when I was returned to the wing.

To Cat D and back again

I first got to Cat D in 1988 and scraped through to the PRES hostel despite drinking heavily and using drugs. There was no MDT in those days and I was fortunate to get into trouble for being drunk only once. However, the hostel meant more social interaction and my 'using' got heavier. I managed to find myself a well-paid job and had no trouble working in a structured

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environment but the problems started after work when the structure disappeared. I was returned to closed conditions, misdiagnosed as having an Antisocial Personality Disorder and eventually put on psychotropic medication.

I was placed in a prison hospital after a further misdiagnosis of schizophrenia, which led to a medical board recommending I be sent to a Regional Secure Unit. However, when I saw a doctor from the unit he said I was not mentally ill. I had problems but it was not necessary to place me in a Regional Secure Unit. I was weaned off medication and returned to the wing. From there I was sent to a Cat C and after an overdose was put on a detoxification programme and have now been clean for almost seven years.

Diagnosis

In 1999 an outside psychiatrist was brought in to do lifer parole reviews and fortunately I was one of the lifers she saw. After reading my history and speaking to me she discussed the possibility that I had Asperger Syndrome. I agreed to be tested and the initial diagnosis was shown to be correct. I am fortunate in the sense that I am High Functioning and capable of learning if the right lessons are delivered.

Being aware of what is wrong with me, and understanding that I am not alone, has enabled me to make tremendous steps forward. There is now light at the end of the tunnel and it also helps that I am now able to make others aware of my condition and receive support and understanding rather than being punished for my behaviour. I have been able to venture out of my safe world of mathematics and start to plan a future for myself, with the help of specialists. I studied mathematics in order to stay out of trouble. I enjoyed the subject because of its structure, lack of ambiguity and universal nature. I have the option to start part B of a doctorate in 2003 and others tell me how well I have done but I was just in my safe world taking advantage of a gift I have. Now I am aware of my condition I will probably not complete my doctorate but study how best to survive in the real world and help others with Asperger Syndrome.

I agreed to write this article in the hope that prison staff may recognise some of the symptoms in prisoners they deal with and may possibly persuade such prisoners to be tested for Asperger Syndrome. In hindsight, it is difficult to know how else the prison system could have coped with me since it is a hidden disability, which needs specialist diagnosis. What follows is a brief description of Asperger Syndrome based on notes from a Staff Awareness Session held in my current prison and delivered by Andrew Powell, Project Officer of The National Autistic Society.

Autism

Asperger Syndrome is an Autistic Spectrum

Disorder that affects the thinking and behaviour of individuals. Autism was first identified in 1943 by Leo Kanner who provided this definition:

'Autistic individuals have come into the world with an innate inability to form the usual biologically provided affective contact with people' (Kunner, 1943, p250).

It is an invisible, life-long disability which affects how people relate to others around them and from which more men than women suffer. It can affect people with severe learning disabilities as well as those in MENSA! There are genetic and other causes and there is no 'cure'. Sight, hearing, taste, smell, touch are the five senses and Autism has been likened to a missing 'sixth sense' — Social Intuition. People with autism are sometimes described as living in a world of their own:

'I really did not know there were people until I was seven years old. I then suddenly realised that there were people. But not like you do ... I could never have a friend. I really do not know what to do with other people' (Donald Cohen, 1980, p388).

Autism is a complex developmental disability, which affects the way a person makes sense of the world around them.

'Reality to an autistic person is a confusing interacting mass of events, people, places, sounds and sights ... a large part of my life is spent just trying to work out the pattern behind everything' (Jim Sinclair).

Autism is defined by the 'triad of impairments'. All people with autism (regardless of IQ etc.) have impairments in: Social Communication, Social Interaction and Social Imagination.

Asperger Syndrome

Asperger Syndrome was first described by Hans Asperger in 1944 and the term was first used by doctor Lorna Wing in 1981. It is usually used to describe people with autism who have relatively good language skills, and an IQ above 70. It affects more males than females and approximately one person in 300. However, with the right support people with Asperger Syndrome are often able to live quite independent lives. Without support they can be prone to depression, anxiety and social isolation. The single best support is a person who has knowledge of Asperger Syndrome.

As soon as we meet a person, we make all sorts of judgements. Just by looking we can often guess their age and status, and by the expression on their face what emotions they are feeling. This enables us to judge what to say, and how to say it. We intuitively adapt to the other person, without much 'thought'. To someone with Asperger Syndrome this does not come intuitively.

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This is the central difficulty for someone with Asperger Syndrome.

Asperger Syndrome and the 'triad of impairment'

Someone with Asperger Syndrome may have a number of difficulties with *social communication*. They may, for example, struggle to know what to say to other people; use odd or inappropriate language; have difficulty in understanding what others say and in processing the meaning of what is said; and, either miss altogether or misinterpret non-verbal communication. Consequently, the person with Asperger Syndrome may understand what is said literally, misunderstand jokes and be unable to sustain conversation.

Similarly, the *social interaction* difficulties experienced by someone with Asperger Syndrome can also isolate them from a range of everyday activities which are fundamental to living with other people. People with Asperger Syndrome often do not know what to do when with other people; do not make friends easily and misunderstand unwritten rules of behaviour. Consequently they may appear odd, or indifferent to others' attempts to engage them and may become socially vulnerable.

The third aspect of the triad of impairment associated with Asperger Syndrome are the difficulties with the *social imagination*. These can include problems with imagining what others are thinking and feeling; not understanding the consequences of actions; imagining 'choices'; and flexibility of thought. This inability to understand others' thoughts and feelings comes from a poor concept of self, of what it means to be a social being. Dr Simon Baron Cohen (1996) calls this 'mind-blindness'.

'I live behind a glass screen.' (person with Asperger Syndrome)

Because of their difficulties with social imagination, the person may:

- Appear 'cold' to others feelings.
- Not think about the impact of what they say.
- · Not see the 'bigger picture', and focus on 'trivia'.
- · Become socially vulnerable.
- Be unable to sequence events.
- Resist change.
- Need to know everything.
- Not get jokes.

Other characteristics

In addition to the triad of impairment the person with Asperger Syndrome may also experience hypo- or hyper-sensitivity in the five senses.

'A defect in the systems which process incoming sensory

information causes the child to over-react to some stimuli and under-react to others'

(Temple Grandin, 1986, p9).

'I learned to lose myself in anything I desired — the patterns on the wall paper or the carpet, the sound of something over and over again, the repetitive hollow sounds I'd get from tapping my chin ...'

(Donna Williams, 1992, P9)

As a consequence people with Asperger Syndrome are at greater risk of suffering from mental health problems. This can be linked to many factors including increases in insight, perceived threats and stress, as well as organic factors. It can be difficult to separate autism from other problems — depression being the most common mental health problem. People can also develop obsessions, compulsions, panic attacks, paranoia and delusions, etc. Other health problems, such as epilepsy, attention deficit, tics and movement disorders, can also occur.

Practical Responses to Asperger Syndrome

Every person with Asperger Syndrome is an individual. Each person requires a tailored response. Asperger Syndrome is the start of the assessment — it is a signpost to help you know which direction to take. Asperger Syndrome is a complex mixture of strengths and weaknesses, expect the unexpected! The National Autistic Society uses 'SPELL' as a framework or philosophy to underpin work with individuals who have autism. SPELL is an acronym: Structure, Positive, Empathy, Low arousal and Links

Together the aspects of the SPELL framework to Asperger Syndrome provide a basis for working with and relating to people with Asperger Syndrome. The following summarises how you can respond in practical ways to people with Asperger Syndrome.

- · Take time to get to know the individual.
- Be flexible whenever possible.
- Take pressure off AS = Anxiety / Stress.
- · Clear, calm, consistent support.
- Written or visual prompts, can be useful to back up verbal information.
- Read about Asperger Syndrome try to see the world through the eyes of someone with Asperger syndrome.
- · Show empathy.
- Do not expect quick permanent changes long-term support is often necessary.

Useful contacts: Autism Helpline — 0870 600 8585 for parents; Information centre for professionals — 020 7903 3599; Parent to Parent — 0800 9520 520; Training — 0115 911 3363; .Website 'www.nas.org.uk'