

The Autism Epidemic – Real or Imagined

By Tony Attwood

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Asperger's Syndrome was originally described in 1944 but has only recently been accepted as a Pervasive Developmental Disorder and part of the Autistic Spectrum. Thus we have little research on the nature and prevalence of this syndrome to determine whether the increase in referrals is simply due to greater knowledge about the syndrome or a genuine epidemic. A useful starting point is to consider the different pathways to a diagnosis and whether certain factors are contributing to the increase in children and adults being diagnosed with Asperger's Syndrome.

In my original book on Asperger's Syndrome, I outlined six pathways. The first was a diagnosis of classic autism in early childhood. The child may have been silent and socially aloof at age three years but due to the benefits of intensive early intervention programs, progresses along the Autism Continuum to the point where the descriptions of Hans Asperger, rather than Leo Kanner, more accurately describe the child's profile of abilities.

Our research on classic autism could explain some of the factors that appear to have contributed to an increase in the incidence of such children. For example, research in the 1980s indicated an increased risk of autism with increasing maternal age. In current western society, women are tending to delay having children to complete their qualifications and establish their careers. Another interesting suggestion is that migration from geographically distant cultures could be correlated with autism. One explanation may involve the immune system and the knowledge from research studies that autism can be a consequence of certain infections in pregnancy and infancy. Jet travel to exotic countries is now more affordable and increasingly popular. However, there may be an increased risk of contracting exotic infections. There is also some debate as to whether certain toxins in our modern society may affect brain development or contribute to inborn errors of metabolism that could result in autism. All these factors may contribute to a genuine increase in autism and after the effects of early intervention programs, a subsequent diagnosis of Asperger's Syndrome.

The second pathway is the recognition of the characteristic signs when the child first starts school. There may have been no signs of classic autism in the pre-school years but the teacher recognises a distinct profile of abilities and first raises the question of whether the child has Asperger's Syndrome. The child is then referred for a diagnostic assessment. This procedure should be straight forward but this is not always the case. Relevant knowledge and experience among clinicians is notoriously variable. There are few professional training courses on diagnostic procedures, which lead to a potential lack of validity and reliability in diagnosis. The same child may be diagnosed as having Asperger's Syndrome by one clinician while another diagnoses Oppositional Defiant Disorder with signs of Obsessive Compulsive Disorder.

There is also some disagreement regarding the diagnostic criteria. The criteria in DSM IV (the most commonly used criteria) have been described in the research literature as "inadequate", "unworkable" and not describing the cases in the original study by Hans Asperger. Some clinicians and academics have now abandoned the differential criteria regarding the development of "normal" cognitive skills, language, curiosity and self-help skills and the obligation to diagnose autism if the child fulfils the criteria for both autism and Asperger's syndrome. This "loosening" of the criteria will inevitably lead to an increase in the number of people diagnosed with Asperger's Syndrome.

We are also unsure where to draw the line at the lower and upper levels of expression. Should children with an intellectual disability be excluded from the diagnosis? Clinicians are divided on this issue such that some individuals with an IQ above 60 would be diagnosed as having the disorder by some clinicians while others would exclude this diagnostic option on the basis of the person's IQ. There is also the issue of whether to use the term High Functioning Autism versus Asperger's Syndrome. Current research is determining whether there are any significant differences between individuals considered to have High Functioning Autism compared to those with Asperger's Syndrome as defined in DSM IV. There may be some differences in specific areas of functioning but whether

these should be mutually exclusive diagnostic “boxes” is currently being debated in the academic literature.

We have yet to explore the upper levels of expression and at what point a developmental disorder becomes a personality disorder or just a personality type. We know that some individuals with Asperger’s Syndrome can improve specific skills and effectively camouflage their unusual profile of abilities. Some authorities restrict the diagnosis only to those who are significantly disabled while others such as the present author would include those who are successfully employed, married and do not need psychiatric services or welfare as having signs of residual Asperger’s Syndrome. For such individuals the profile is at a more advanced or mature level of expression than Hans Asperger’s seminal description of children.

Another pathway is the diagnosis of a relative with autism or Asperger’s Syndrome and knowledge within the family of this condition leads to the identification of others within and between generations who share the same characteristics. Recent research on the genetics of Asperger’s syndrome has produced some interesting results. A study at Yale University examined the profile of abilities of 99 families that had a child with Asperger’s Syndrome. In 46% of the families there was a positive family history of Asperger Syndrome or something very similar in first-degree relatives. What may be termed the broader autism phenotype is probably more common in families than we first thought. At present we do not have any clear guidelines as to whether such individuals should have a diagnosis of Asperger’s Syndrome, residual Asperger’s Syndrome, the genetic term of broader autism phenotype or (the author’s preference) the Asperger’s personality type.

We also know that the siblings of a child with Asperger’s Syndrome may have what the present author calls “fragments” of Asperger’s Syndrome in their profile of abilities. The individual characteristics may not be sufficient in number or severity for a clear diagnosis but if we are unsure where the boundaries are between the normal range and Asperger’s Syndrome, then such children could be considered by some clinicians as having the diagnosis, especially if this created a better understanding of the person and access to remedial programs known to be effective with those who have the complete syndrome.

A fourth pathway is a dual diagnosis. The author’s clinical experience suggests an increasing number of referrals of children with Attention Deficit Disorder who are subsequently diagnosed as having Asperger’s Syndrome. The signs of ADD are well known and may be identified in a very young child but specialists in ADD are becoming increasingly aware of the need to screen for other disorders associated with ADD and this has contributed to the increase in referrals and confirmed dual diagnosis.

The present author has noted that some referrals are subsequently recognised as having a combination of four distinct but probably linked disorders. The typical sequence is to identify signs of ADD, followed by signs of Asperger’s Syndrome, then the facial, motor, vocal and behavioural tics associated with Tourette’s Disorder and finally a mood disorder such as Obsessive Compulsive Disorder.

The fifth pathway is the diagnosis of a secondary psychiatric disorder, especially depression. The depression may have the typical clinical signs but for some individuals, episodes of extreme anger and substance abuse are the first signs. Clinicians subsequently confirm a diagnosis of Asperger’s Syndrome based on the person’s developmental history and profile of abilities and the fact that the person has an agitated, externalised depression (the focus of anguish is on others rather than themselves) or alcohol and non-prescription drugs are used as a form of self-medication. Psychiatric services are gradually becoming aware of the value of screening for Asperger’s Syndrome, which can be associated with a number of psychiatric disorders.

The sixth pathway is a diagnosis that occurs in the person’s adult years. This can be due to the recognition of the condition by employment agencies, the person reading information in the popular press and watching television documentaries or the criminal justice system recognising the profile. I would now add another mechanism, namely relationship counselling agencies and recognition of the condition by the partner of the person with Asperger’s Syndrome. I have recently had an increase in

referrals of wives who arrange an appointment because they think that their husband has Asperger's syndrome. The partner reads about Asperger's Syndrome and realises that this could explain their relationship problems. However, one must remember that not all "men behaving badly" have Asperger's Syndrome.

A new or seventh pathway is posthumous diagnosis. We recognise that people with Asperger's Syndrome have a different way of thinking and that some are remarkably creative and perceptive. The characteristics can lead to an illustrious career in science and the arts. Indeed, it is the author's opinion that we need people with Asperger's Syndrome to continue to improve the quality of our lives. We are currently examining the biographies and autobiographies of famous deceased scientists, engineers, politicians, authors and composers and recognising that for some, their unusual childhood and profile of abilities could be indicative of Asperger's Syndrome. Examples of possible "Asperger's Achievers" are Albert Einstein, Thomas Jefferson, Mozart, Ludwig Wittgenstein, Glenn Gould and Alan Turing. The author also knows of several adults with Asperger's Syndrome who are remarkably skilled in identifying signs of Asperger's Syndrome in contemporary scientists, actors, rock musicians and writers. At present such potential diagnoses remain pure conjecture but such illustrious individuals could be valuable heroes to children with Asperger's Syndrome.

Another factor, which may explain the increase in genuine referrals, is our increasing understanding of the profile of abilities in girls and women with Asperger's Syndrome. The profile can include special interests in animals, classic literature and acting rather than transport, computers and electronics. Girls may be more able to learn social skills by observation and imitation than boys and be less conspicuous in the classroom as other girls may "mother" and protect them and they are less prone to anger and being disruptive.

A factor which may be inhibiting the diagnosis of Asperger's Syndrome, is that Government agencies may not have policies and resources for such individuals, and to gain access to services an alternative diagnosis must be written on the application form or be used in the clinician's report. For example, some children may only have support in the classroom; parents receive government allowances or Medical Insurance cover if the child has a diagnosis of Autism. Clinicians may write reports with a diagnosis of autism rather than the more accurate diagnosis of Asperger's syndrome. This is particularly relevant when one considers the initial epidemiological research suggests that one person in 250 has signs of Asperger's syndrome. Government and non-government agencies, especially Education departments have usually not been funded for such an incidence and are reluctant to "open the floodgates".

In conclusion, is there an epidemic of people being diagnosed as having Asperger's Syndrome? At present we cannot answer the question, as we are unsure of the diagnostic criteria, the upper and lower levels of expression and the borders with other conditions. Nevertheless, we are experiencing a huge increase in diagnosis but this may be the backlog of cases that have been waiting so long for an explanation. At long last, we know why such individuals are different and finally we can learn how to understand each other.