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Is Asperger's syndrome necessarily a disability?

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Abstract

This article considers whether Asperger Syndrome (AS) should necessarily be viewed as a disability or from a different perspective, as a 'difference'. It concludes that the term 'difference' in relation to AS is a more neutral, value-free, and fairer description, and that the term 'disability' better applies to the lower functioning cases of autism. But it recognizes that the term 'disability' may need to be retained for AS as long as the legal framework only provides financial and other support for individuals with a disability. A model is summarized which attempts to define in what way individuals with AS are 'different': the empathising-systemising model.

Autism is viewed as a ‘psychiatric condition’, a ‘disorder’, a ‘disability’ or a ‘handicap’. Ever since Kanner’s description of the ‘aloneness’ of these children (Kanner, 1943), psychiatry has labelled and categorised them as abnormal, ill, and deficient. Through the changing definitions of autism enshrined in successive editions of both DSM (Diagnostic and Statistical Manual, published by the American Psychiatric Association) or ICD (International Classification of Diseases, published by the World Health Organisation), we have had a single view of autism thrust upon us: an essentially negative view in which children or adults with autism are characterised as “impaired” (APA, 1994).

This article challenges this view as applied to all autism spectrum conditions. Whereas the disability view might be clearly appropriate for classic autism, the article suggests that from a particular perspective, the close relative of autism, called Asperger Syndrome, can be viewed simply as a *different* cognitive style. This important idea can be traced to Uta Frith’s book (Frith, 1989), and has been recently discussed in relation to ‘central coherence’ theory (Happe, 1999), but deserves a fuller discussion because of the implications of this shift of emphasis.

Asperger's syndrome (AS)

Autism is diagnosed on the basis of abnormalities in the areas of social development, communicative development, and imagination, together with marked repetitive or obsessional behaviour or unusual, narrow interests (APA, 1994). Individuals with autism may have an IQ at any level. By convention, if an individual with autism has an IQ in the normal range (or above), they are said to have 'high-functioning autism' (HFA). If an individual meets all of the criteria for HFA except communicative abnormality/history of language delay, they are said to have Asperger's syndrome (AS). In this paper, we focus on AS and HFA since we accept that an individual who is lower-functioning necessarily has a disability in the form of retardation. What is not clear, and therefore the subject of the debate presented next, is whether individuals with AS necessarily have a disability. For the present purposes, we consider the arguments in relation to AS and HFA, without attempting to draw any distinction between these.

The arguments for viewing AS as a difference rather than a disability

1. Behaviour in AS is not better or worse than that seen in typical development

If one examines the facts, attempting to be non-judgmental about them, children with AS could be said to show the following differences. (These are based on diagnostic features, except where alternative citations are given.)

1. The child spends more time involved with objects and physical systems than with people (Swettenham et al., 1998);
2. The child communicates less than other children do;

3. The child tends to follow their own desires and beliefs rather than paying attention to, or being easily influenced by, others' desires and beliefs (Baron-Cohen, Leslie & Frith, 1985);
4. The child shows relatively little interest in what the social group is doing, or being a part of it (Bowler, 1992; Lord, 1984);
5. The child has strong, persistent¹ interests;
6. The child is very accurate at perceiving the details of information (Plaisted, O'Riordan & Baron-Cohen, 1998a; Plaisted, O'Riordan & Baron-Cohen, 1998b);
7. The child notices and recalls things other people may not (Frith, 1989);
8. The child's view of what is relevant and important in a situation may not coincide with others (Frith, 1989);
9. The child may be fascinated by patterned material, be it visual (shapes), numeric (dates, timetables), alphanumeric (number plates), or lists (of cars, songs, etc.);
10. The child may be fascinated by systems, be they simple (light switches, water taps), a little more complex (weather fronts), or abstract (mathematics);
11. The child may have a strong drive to collect categories of objects (e.g., bottle tops, train maps), or categories of information (types of lizard, types of rock, types of fabric, etc.); and
12. The child has a strong preference for experiences that are controllable rather than unpredictable.

¹ 'Persistent' here does not necessarily mean for years, but certainly for extended periods of time. Typical reports describe intense interests lasting for months, but which then switch to new, equally intense topics.

The list could be expanded but these 12 behavioural features are sufficient to illustrate that children with AS are different in ways that can be described in value-free terms: none imply any necessary disability. Rather, most of the above facts show the child as immersed in the world of things rather than people. This might be a basic way of defining the difference between a person with an autism spectrum condition and one without it (Baron-Cohen, 2000).

Being more object-focused than people-focused is clearly only a disability in an environment that expects everyone to be social. But a moment's reflection highlights the injustice of this expectation. Thus, people who show the opposite pattern (of being more people-focused than object-focused) are not necessarily considered disabled. On this view, people with AS would cease to be disabled as soon as society's expectations change. For example, a child with AS who prefers to stay in the classroom poring over encyclopaedias and rock collections during break-time, when other children are outside playing together, could simply be seen as different, not disabled. It is not clear why the child with AS is seen as doing something less valuable than the other children or why their behaviour should be seen as an index of impairment.

Equally, a child with AS who has strong narrow interests of an unusual nature (learning the names of every kind of bird) may be different to a typical child who has only been interested to learn the names of common animals. But surely the narrow deep knowledge is no less valuable than the broad, shallower variety, and certainly not a necessary index of deficit? A final example should help drive this point home. Just because a child with AS notices the unique numbers on lamp-posts which the rest of us are unaware of, does this make him impaired? We could say it is simply different. The same argument can be applied to all of the other facts listed above.

II. The neurobiology of AS is not better or worse than in typical development.

AS involves a range of neural differences. A full review of these is beyond the scope of this article, but the reader can consult other excellent summaries (Piven et al., 1995; Piven, Bailey, Ranson & Arndt, 1998; Piven et al., 1990). In some regions of the brain increased cell density has been found (Bauman & Kemper, 1988), - for example, in the limbic system - whilst in other regions of the brain structures are reported to be smaller. For example, the cerebellar vermis lobule 7 (Courchesne, Yeung-Courchesne, Press, Hesselink & Jernigan, 1988) and the posterior section of the corpus callosum (Egaas, Courchesne & Saitoh, 1995) have both been reported to be reduced in size in autism. However, whilst these neural abnormalities signal differences between brains of people with and without AS, they cannot be taken as evidence that one type of brain is better or worse than the other.

Similarly, AS appears to be strongly familial, implying a genetic aetiology, and the first report from an international molecular genetic consortium study reported a linkage on Chromosome 7 in affected individuals (Bailey, Bolton & Rutter, 1998). The molecular genetic basis of AS remains to be worked out in detail, but again such findings are at best evidence of difference and in no way implies that the genotype of AS is deficient.

III. 'Difference' avoids value-laden judgements

Many features of AS may be redescribed in ways that are more neutral, in terms of AS comprising a different 'cognitive style', with no implication that this is better or worse than a non-autistic cognitive style (Happé, 1999). For example, the AS cognitive style

may be described as being more object-oriented, and more focused on detail². Another change in terminology is that the term ‘autistic spectrum disorders’ is being replaced by the term ‘autistic spectrum conditions’. Like the term ‘cognitive style’, this avoids the possibly pejorative associations of the term ‘disorder’, though it may be questioned whether even using the term ‘condition’ is an appropriate medicalizing of an individual’s cognitive style. But the spirit of such changes in terminology is clear. It is possible to describe AS in value-free ways.

IV. The difference view is more compatible with the ‘continuum’ concept

A further argument for favouring the difference view over the disability view is that it is easier to accommodate within the now widely accepted notion that autism appears on a continuum (Wing, 1988). The notion of a continuum assumes that there is an underlying dimension or set of dimensions along which all people vary. There is still debate over precisely what constitutes the underlying dimension. Later in the paper we consider a model which aims to characterise the autistic spectrum.

Arguments for viewing AS as a disability rather than a difference

² Temple Grandin, at the recent Geneva Centre Conference on autism in Toronto (November 1998) said “What would happen if you eliminated the autism genes from the gene pool? You would have a bunch of people standing around in a cave, chatting and socialising and not getting anything done!” This anecdote nicely illustrates that the genes for autism may lead to a different cognitive style that has enormous practical value in its own right (Baron-Cohen et al., 1998; Baron-Cohen, Wheelwright, Stott, Bolton & Goodyer, 1997).

A research assistant with Asperger Syndrome working at Yale gave me another anecdote. He said “If we are autists, you guys are heterists. The diagnostic features of heterists are making lots of eye contact, and overlooking details such as small coins on patterned carpets or car number plates.” Again, this anecdote emphasises our differences, and raises the question in an amusing way about why one style should be regarded as a disability.

1. Lack of social interest reflects disability

Here is a first argument for seeing AS as a disability: the absence of a behaviour may itself reflect a disability in that area. In this case, the lack of normal sociability or communication is seen as a sign of disability. But this can be seen as unfair: it calls attention to what someone does not do (so well, or so much) in the case of AS, when we do not do this in the case of people without AS. For example, I do not spend much, if any, time thinking about mathematics problems, but I spend quite a lot of time thinking about people. In contrast, the person in the next door office spends a lot of time thinking about mathematics problems, and hardly any thinking about people. Yet I do not describe myself as having a disability in mathematics. I would instead say that I simply prefer to spend time thinking about people: they are more interesting to me. To call what a person does little of a disability could be seen as unreasonable. It might be a little like saying that the basketball player Michael Jordan has a deficit in fine motor coordination on the grounds that he is not known for spending much (if any) time engaged in needlework. This may be true of him, but to highlight this aspect of his skills, whilst ignoring his obvious assets in hand-eye coordination, physical speed, strength, agility, etc., is to put things back to front, and would be an unfair description of him.

2. Empathy deficits

The second rejoinder to the difference argument is that children with AS show differences precisely because they are disabled, impaired, suffer cognitive deficits, etc. Thus, one might argue that they are less influenced by others because they do not spontaneously stop to consider other people's points of view, feelings and thoughts (the theory of mind or empathy deficit) (Baron-Cohen, Jolliffe, Mortimore & Robertson, 1997; Baron-Cohen, Leslie & Frith, 1985); they may communicate less and may be less

socially focused for the same reason. For these reasons, the rejoinder goes, we should retain the notion of AS as a disability. It is possible that reduced empathy may not be viewed by the person with AS as a disability, but this is particularly powerful as an argument when the impact of empathy deficits on other people is considered: it can be very hard for the family or partner or peer group of people with AS to be in a relationship with someone for whom empathy does not come naturally. This view has considerable weight, and it remains likely that as long as the expectations on a person with AS to be empathic are high, problems may occur.

3. AS is a disability because it involves special needs and extra support

Perhaps the most compelling reason for viewing AS as a disability is that such individuals clearly have special needs (they need to be recognised as different, may require different kinds of teaching methods or schooling, or specific kinds of treatment) and access to such support in the present legal framework only flows to the child and their family if the case can be made that autism is a disability. Special funding does not automatically flow simply because one regards the child as ‘different’. Given this economic reality, one should not remove the term ‘disability’ from the description of AS without ensuring that extra provision would still be available even if the term ‘difference’ was more appropriate. This is really an issue relating to social policy, health and education economics, and the legal system.

In concluding this section, we can see that AS can be viewed as a disability from the perspective of others (on the receiving end of reduced empathic behaviour) and from the perspective of accessing funding for support.

The Empathising-Systemising Model

We turn next to consider a new model which attempts to characterise the dimension(s) along which AS differs from ‘normality’. The model suggests that the two relevant dimensions along which to characterise individuals with AS might be ‘empathising’ and ‘systemising’. Empathising involves understanding how people work. Systemising involves understanding how inanimate things work. The model assumes that all individuals on the autistic continuum show degrees of empathising impairment, whilst their systemising may be intact or even superior, relative to their mental age (Baron-Cohen, 2000; Baron-Cohen & Hammer, 1997a). This model is shown in Figure 1.

insert Figure 1 here

Empathising

There is plenty of evidence that people with autism spectrum conditions have degrees of difficulty in mind-reading, or empathising. There have been more than 30 experimental tests, the vast majority revealing profound impairments in the development of their folk psychological understanding. These are reviewed elsewhere (Baron-Cohen, 1995; Baron-Cohen, 2000) but include deficits in understanding complex emotions (Baron-Cohen, 1991). Some adults with AS only show their deficits on age-appropriate adult tests of empathising (Baron-Cohen et al., 1997; Baron-Cohen, Wheelwright & Jolliffe, 1997; Happe, 1994). This deficit in their empathising is thought to underlie the

difficulties such children have in social and communicative development (Baron-Cohen, 1988; Tager-Flusberg, 1993).

Systemising

Other evidence suggests that children with AS may not only be intact but also superior in their systemising. First, clinical and parental descriptions of children with AS frequently refer to their fascination with machines [the paragon of non-intentional systems] (Hart, 1989; Lovell, 1978; Park, 1967). Indeed, it is hard to find a clinical account of autism spectrum conditions that does *not* involve the child being obsessed by some machine or another. Examples include extreme fascinations with electricity pylons, burglar alarms, vacuum cleaners, washing machines, video players, calculators, computers, trains, planes, and clocks. Sometimes the machine that is the object of the child's obsession is quite simple (e.g., the workings of drain-pipes, or the design of windows, etc.). A systematic survey of obsessions in such children has confirmed such clinical descriptions (Baron-Cohen & Wheelwright, 1999).

The child with AS may be described as holding forth, like a "little professor", on their favourite subject or area of expertise, often failing to detect that their listener may have long since become bored of hearing more on the subject. The apparently precocious mechanical understanding, whilst being relatively oblivious to their listener's level of interest, suggests that their systemising might be outstripping their empathising in development. The anecdotal evidence includes not just an obsession with machines, but

with other kinds of systems. Examples include obsessions with the weather (meteorology), the formation of mountains (geography), motion of the planets (astronomy), and the classification of lizards (taxonomy).

Leaving clinical/anecdotal evidence to one side, experimental studies converge on the same conclusion, that children with AS not only have an intact systemising, they have accelerated or superior development in this domain (relative to their empathising and relative to their mental age, both verbal and nonverbal). First, two studies have found that children with autism showed good understanding of a camera (Leekam & Perner, 1991; Leslie & Thaiss, 1992). In these studies, children with autism could accurately infer what would be depicted in a photograph, even though the photograph was at odds with the current visual scene. This contrasted with their poor performance on False Belief tests. The pattern of results by the children with autism on these two tests was interpreted as showing that whilst their understanding of mental representations was impaired, their understanding of physical representations was not. This pattern has been found in other domains (Charman & Baron-Cohen, 1992; Charman & Baron-Cohen, 1995). But the False Photo Test is also evidence of their systemising outstripping their empathising and being superior to mental age (MA) matched controls.

Family studies add to this picture. Parents of children with AS also show mild but significant deficits on an adult empathising task, mirroring the deficit in empathising seen in patients with AS (Baron-Cohen & Hammer, 1997b). This is assumed to reflect genetic factors, since AS appear to have a strong heritable component (Bailey et al., 1995; Bolton

et al., 1994; Folstein & Rutter, 1977; Le Couteur et al., 1996). On the basis of this model, one should also expect that parents of children with autism or AS to be over-represented in occupations in which possession of superior systemising is an advantage, whilst a deficit in empathising would not necessarily be a disadvantage. The paradigm occupation for such a cognitive profile is engineering.

A recent study of 1000 families found that fathers and grandfathers (patri- and matrilineal) of children with autism or AS were more than twice as likely to work in the field of engineering, compared to control groups (Baron-Cohen et al., 1997). Indeed, 28.4% of children with autism or AS had at least one relative (father and/or grandfather) who was an engineer. Related evidence comes from a survey of students at Cambridge University, studying either sciences (physics, engineering, or maths) or humanities (English or French literature). When asked about family history of a range of psychiatric conditions (schizophrenia, anorexia, autism, Down Syndrome, language delay, or manic depression), the students in the science group showed a six-fold increase in the rate of autism in their families, and this was specific to autism (Baron-Cohen et al., 1998).

Finally, children with AS have been found to perform at a superior level on a test of systemising (Baron-Cohen, Wheelwright, Scahill & Spong, submitted), and some adults with AS have reached the highest levels in physics and mathematics, despite their deficits in empathising (Baron-Cohen, Wheelwright, Stone & Rutherford, in press).

The advantage of this model is that individuals with AS are understood in terms of an underlying dimension, and that this dimension blends seamlessly with normality, so that we are all situated somewhere on the same continuum. Most importantly, to reiterate, one's position on the continuum is said to reflect a different cognitive style (Frith, 1989). Dimensional models also do show clear line to be drawn between ability and disability.

Finally, they avoid the notion that individuals with AS are in some sense qualitatively different from those without AS. Such a notion is increasingly hard to defend in the light of intermediate cases. These are easier to accommodate in terms of quantitative variation.

Implications for understanding the apparent increase in prevalence of AS

There are some reports that AS is increasing in prevalence (Gillberg & Wing, 1999). It is unclear if this simply reflects better detection or if there is a genuine increase. However, if there is a genuine increase, this presents something of a paradox for the disability view: disabilities with a genetic basis which affect social skill and thus potentially reduce mating opportunities should be subject to *negative* selective pressures. Such disabilities should therefore be expected to *reduce* in prevalence with time. In order to be on the increase, such genes would have to be being *positively* selected. Increased prevalence presents no difficulties for the difference view however, since a cognitive style can at different times or under different conditions confer *advantages* to the individual. For example, the computer revolution in the 20th Century has created unprecedented opportunities for employment and economic prosperity for individuals with superior systemising. This may have had positive effects on the reproductive fitness of such individuals, leading to an increase in the genes for AS in the gene pool. Such a speculation is testable: for example, one would predict higher rates of AS in the children of couples living in environments which function as a niche for individuals with superior folk-physics abilities (e.g. 'Silicon Valley', MIT, Caltech) compared to environments where no such niche exists. Our recent survey of scientists in Cambridge University showing increased familiarity of autism spectrum conditions is a first such clue that such effects may be operating (Baron-Cohen et al., 1998).

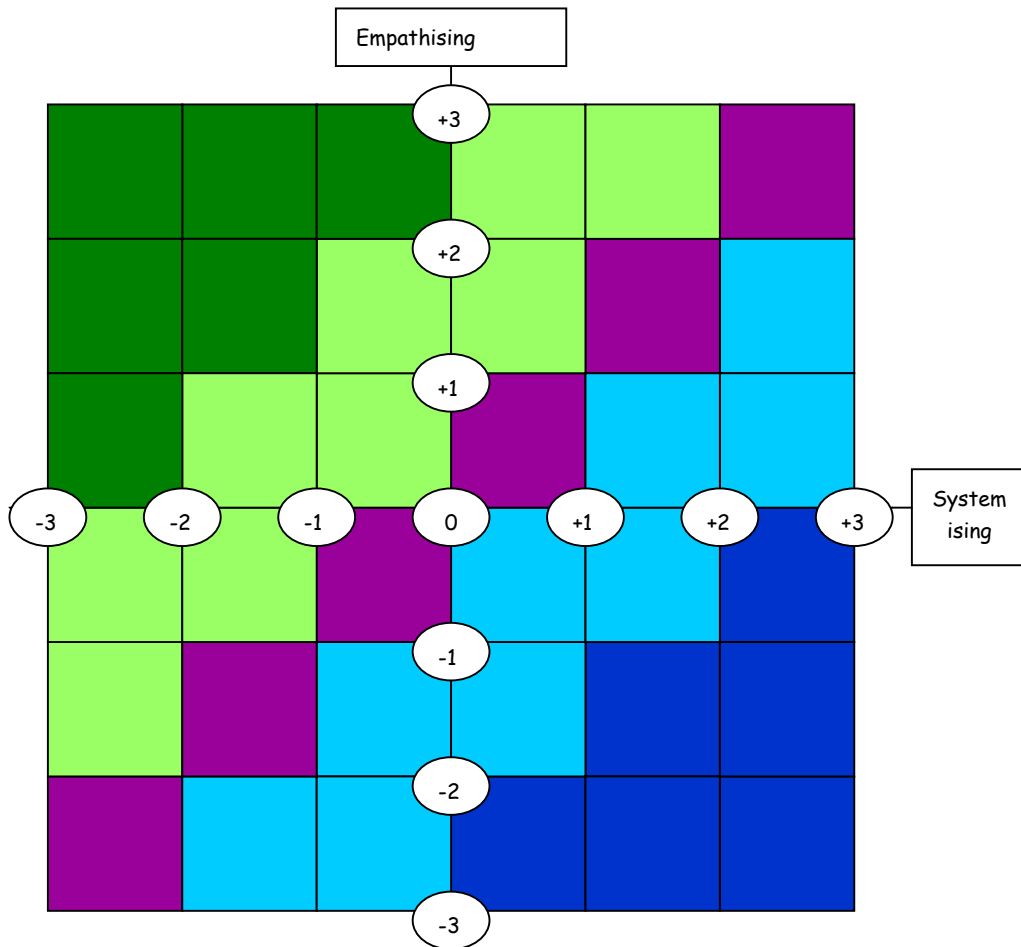
Summary

In a world where individuals are all expected to be social, people with AS are seen as disabled. The implication is that if environmental expectations change, or in a different environment, they may not necessarily be seen as disabled. As we have known in relation to other conditions, concepts of disability and handicap are relative to particular environments, both cultural and biological (Clark, 1999; Richters & Cicchetti, 1993; Spitzer, 1999; Wakefield, 1997). It may be time to extend this way of thinking to the field of AS. Equally, people with AS might not necessarily be disabled in an environment in which an exact mind, attracted to detecting small details, is an advantage. In the social world there is no great benefit to such a precise eye for detail, but in the world of maths, computing, cataloguing, music, linguistics, craft, engineering or science, such an eye for detail can lead to success rather than disability. In the world of business, for example, a mathematical bent for estimating risk and profit, together with a relative lack of concern for the emotional states of one's employees or rivals, can mean unbounded opportunities.

The two reasons for retaining the term disability in relation to AS may be (1) to ensure access to provision; it may be the legal system that needs revision, so that a child whose autistic 'difference' leads them to have special needs, will still receive special support. (2) And to recognize that reduced empathy can create considerable emotional difficulties for those attempting to have a relationship with someone with AS. But to focus exclusively on the disability aspect of AS is to focus only on half of the model outlined. Family support is clearly needed for those in relationships with those with AS, but the non-disabled aspect of AS (intact or even superior systemising) also needs to be recognized.

Figure 1: Empathising and Systemising Dimensions

Empathising (E) and Systemising(S) Dimensions



KEY	
E and S are equal	
E exceeds S	
S exceeds E	
The mirror image of autism/AS	
Autism and AS	

Axes show standard deviations from the mean

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