

Is Asperger Syndrome Necessarily Viewed as a Disability?

Simon Baron-Cohen

This article considers whether Asperger syndrome (AS) should necessarily be viewed as a disability or, from a different perspective, as a difference. The author concludes that the term *difference* in relation to AS is a more neutral, value-free, and fair description, and that the term *disability* better applies to the lower functioning cases of autism. But he recognizes that *disability* may need to be retained for AS as long as the legal framework provides financial and other support only for individuals with a disability. A model is summarized that attempts to define in what way individuals with AS are "different": the empathizing–systemizing model.

Autism is variously viewed as a psychiatric condition, a disorder, a disability, and a handicap. Ever since Kanner's (1943) description of the aloneness of these children, psychiatry has labeled and categorized them as abnormal, ill, and deficient. Through the changing definitions of autism enshrined in successive editions of both the *Diagnostic and Statistical Manual of Mental Disorders* (American Psychiatric Association [APA], 1994) and *International Classification of Diseases* (World Health Organization, 1993), we have had a single view of autism thrust upon us: an essentially negative view in which children or adults with autism are characterized as "impaired" (APA, 1994).

Whereas the disability view might be clearly appropriate for classic autism, the present article suggests that from a particular perspective, the close relative of autism, Asperger syndrome (AS), can be viewed simply as a *different* cognitive style. This important idea can be traced to Frith (1989) and has been recently

discussed in relation to central coherence theory (Happé, 1999), but it deserves a fuller discussion because of the implications of this shift of emphasis.

Asperger Syndrome

Autism is diagnosed on the basis of abnormalities in the areas of social development, communicative development, and imagination, together with marked repetitive or obsessional behavior 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 syndrome. This article focuses on AS and HFA because society generally believes that an individual who is lower functioning 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, the arguments in relation to AS and HFA are considered, without attempting to draw any distinction between these.

The Arguments for Viewing AS as a Difference Rather Than a Disability

Behavior in AS Is Not Better or Worse Than That Seen in Typical Development

If one examines the facts, attempting to be nonjudgmental 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 his or her own desires and beliefs rather than paying attention to, or being influenced by, others' desires and beliefs (Baron-Cohen, Leslie, & Frith, 1985);

4. The child shows relatively little interest in what social groups are doing, or in being a part of them (Bowler, 1992; Lord, 1984);
5. The child has strong, persistent interests (see Note 1);
6. The child is very accurate at perceiving the details of information (Plaisted, O’Riordan, & Baron-Cohen, 1998a, 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 the views of others (Frith, 1989);
9. The child may be fascinated by patterned material, be it visual (shapes); numeric (dates, timetables); alphanumeric (license 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.

The list could be expanded, but these 12 behavioral 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 merely show the child to be 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 a disability only in an environment that expects everyone to be social. But a moment’s reflection highlights the injustice of this expectation. People who show the opposite pat-

tern (of being more people-focused than object-focused) are not considered disabled. People with AS would cease to be disabled if society’s expectations would change. For example, a child with AS who prefers to stay in the classroom poring over encyclopedias 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 behavior should be seen as the index of normalcy.

Equally, a child with AS who has strong but narrow interests of an unusual nature (e.g., learning the names of every kind of bird) may seem different to a typical child who has been interested only in learning the names of common animals. But surely the narrow, deep knowledge is no less valuable than the broad, shallow 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 lampposts, of which the rest of us are unaware, does this make him or her impaired? We could say it is simply *different*. The same argument can be applied to all of the other facts listed above.

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 (e.g., Piven et al., 1995; Piven, Bailey, Ranson, & Arndt, 1998; Piven et al., 1990). In some regions of the brain, such as the limbic system, increased cell density has been found in individuals with AS (Bauman & Kemper, 1988), while 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 with autism.

However, although these neural abnormalities signal differences between the 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 etiology, 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 imply that the genotype of AS is deficient.

“Difference” Precludes Value-Laden Judgments

Many features of AS can be redescribed in ways that are more neutral, in terms of AS including a different cognitive style, with no implication that this is better or worse than a nonautistic cognitive style (Happé, 1999). For example, the AS cognitive style can be described as being more object-oriented and more focused on detail (see Note 2). 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 forestalls the possibly pejorative associations of the term *disorder*, although it may be questioned whether even using *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.

The Difference View Is More Compatible with the “Continuum” Concept

A further argument for favoring 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 that underlying dimension. Later in this article a model that aims to characterize the autism spectrum is introduced.

Arguments for Viewing AS as a Disability Rather Than a Difference

Lack of Social Interest Reflects Disability

The first argument for seeing AS as a disability holds that the absence of a behavior may 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 might 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 say that a person has a disability because he or she rarely does something could be seen as unreasonable. It is 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 while ignoring his obvious assets in hand-eye coordination, physical speed, strength, agility, and so forth, is to put things back to front, and would be an inaccurate description of him.

Empathy Deficits

The second rejoinder to the difference argument is that children with AS show differences precisely because they are dis-

abled, are impaired, suffer cognitive deficits, and so forth. 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 et al., 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 the person 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 for a person with AS to be empathic are high, problems will occur.

AS Is a Disability Because It Involves Special Needs and Requires 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 recognized 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 flows to the child and his or her family only if the case can be made that autism is a disability. Special funding does not flow when a child is "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 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, it is logical to conclude that AS can be viewed as a disability from the perspective of others (on the receiving end of reduced em-

pathic behavior) and from the perspective of accessing funding for support.

The Empathizing-Systemizing Model

A new model has been created that attempts to characterize the dimensions along which AS differs from "normality." The model suggests that the two relevant dimensions along which to characterize individuals with AS are *empathizing* and *systemizing*. Empathizing involves understanding how people work; systemizing involves understanding how inanimate things work. The model assumes that all individuals on the autistic continuum show degrees of empathizing impairment, whereas their systemizing may be intact or even superior, relative to their mental ages (Baron-Cohen, 2000; Baron-Cohen & Hammer, 1997a).

Empathizing

There is plenty of evidence that people with autism spectrum conditions have degrees of difficulty in mind-reading, or empathizing, and in understanding complex emotions. There have been more than 30 experimental tests in this area, the vast majority revealing profound impairments in the development of these individuals' folk psychological understanding (see Baron-Cohen, 1991, 1995, 2000). Some adults with AS show their deficits only on age-appropriate adult tests of empathizing (Baron-Cohen et al., 1997; Baron-Cohen, Wheelwright, & Jolliffe, 1997; Happé, 1994). This deficit in their empathizing is thought to underlie the difficulties such children have in social and communicative development (Baron-Cohen, 1988; Tager-Flusberg, 1993).

Systemizing

Other evidence suggests that children with AS may be not only intact but also superior in their systemizing. 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 drainpipes, the design of windows). A systematic survey of obsessions in these children has confirmed such clinical descriptions (Baron-Cohen & Wheelwright, 1999).

The child with AS is often described as holding forth like a "little professor" on his or her favorite subject or area of expertise, often failing to detect that the listener long since became bored with the subject. The apparently precocious mechanical understanding, combined with oblivion in regard to their listener's level of interest, suggests that these individuals' systemizing is outstripping their empathizing in development. The anecdotal evidence includes an obsession not just with machines but also with other kinds of systems. Examples include obsessions with the weather (meteorology), the formation of mountains (geography), the motion of the planets (astronomy), and the classification of lizards (taxonomy).

Leaving clinical/anecdotal evidence to one side, experimental studies converge around the same conclusion—that children with AS not only have intact systemizing but also have accelerated or superior development in this domain (relative to their empathizing and relative to their mental age, both verbal and non-verbal). 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 inter-

preted as showing that although 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, 1995). But the False Photo Test is also evidence of their systemizing outstripping their empathizing and being superior to that of mental-age-matched controls.

Family studies add to this picture. Parents of children with AS also show mild but significant deficits on an adult empathizing task, mirroring the deficit in empathizing seen in patients with AS (Baron-Cohen & Hammer, 1997b). This is assumed to reflect genetic factors, as AS appears 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 parents of children with autism or AS to be overrepresented in occupations in which possession of superior systemizing is an advantage and a deficit in empathizing is not a disadvantage. The ideal occupation for such a cognitive profile is engineering.

A recent study of 1,000 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 with 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 who were studying either sciences (physics, engineering, or math) 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 sixfold 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 systemizing (Baron-Cohen,

Wheelwright, Scahill, & Spong, 2001), and some adults with AS have reached the highest levels in physics and mathematics, despite their deficits in empathizing (Baron-Cohen, Wheelwright, Stone, & Rutherford, 1999).

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 important, to reiterate, one's position on the continuum is said to reflect a different cognitive style (Frith, 1989). Dimensional models also do show a clear line 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.

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 were to change, or if individuals with AS were set down in a different environment, they would not be perceived as disabled. As we have seen 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). In the social world there is no great benefit to a precise eye for detail, but in the worlds of math, computing, cataloguing, music, linguistics, engineering, and science, such an eye for detail can lead to success rather than failure.

The two reasons for retaining the term *disability* in relation to AS may be (a) to ensure access to provision—it may be the legal system that needs revision so that a child whose autistic "difference" leads him or her to have special needs will still receive special support; and (b) 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 on only half of the model outlined. Family support is clearly needed for those in relationships with individuals with AS, but the nondisabled aspect of AS (intact or even superior systemizing) also needs to be recognized.

ABOUT THE AUTHOR

Simon Baron-Cohen, PhD, is professor of developmental psychopathology at the University of Cambridge in the Departments of Experimental Psychology and Psychiatry; fellow in experimental psychology at Trinity College, Cambridge; co-director of the Autism Research Centre in Cambridge; and director of the Cambridge Lifespan Asperger Syndrome Service. Dr. Baron-Cohen has conducted extensive research into autism spectrum conditions at the psychological, diagnostic, and neuroscientific levels. Address: Simon Baron-Cohen, Autism Research Centre, Departments of Experimental Psychology and Psychiatry, University of Cambridge, Downing St., Cambridge, CB2 3EB, UK.

AUTHOR'S NOTES

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NOTES

1. "Persistent" here does not necessarily mean for years, but certainly for extended periods of time. Typical reports describe intense interests lasting for months, with then a switch to new, equally intense topics.
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 socializing 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 emphasizes our differences, and raises the question in an amusing way about why one style should be regarded as a disability.

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