Asperger's syndrome – Difference or disorder?

Louise Elliman looks at the strengths associated with Asperger's syndrome, from a social model of disability perspective

There is currently much controversy over the status of Asperger's syndrome (AS) and how individuals with AS should be viewed within society. Is AS a disorder in need of diagnosis and treatment, or even curing if that were possible? Or should AS be seen as a personality difference – the extreme end of a spectrum of traits possessed by many individuals in the general population to some extent? Has AS become a disability solely due to unfair barriers within society? Or can the social difficulties faced by those with AS still be appropriately viewed as a direct consequence of their underlying impairments?

questions

Research suggests that a high percentage of individuals with AS also have mental health problems. How does this impact on the question of whether AS is seen as a difference or a disorder? Should the social model be applied to the mental health problems faced by those with AS?

It is generally accepted that Asperger's syndrome (AS) lies within the autism spectrum, and as such it has long been seen entirely as a developmental disorder consisting of impairments in social interaction, social communication and imagination (Wing & Gould, 1979). However, in addition to the known difficulties associated with AS it has recently been argued that in some individuals there are also many associated strengths (e.g. Baron-Cohen, 2002). These are not merely the positive character traits that individuals may possess *despite* their AS, but genuine strengths that many individuals possess *because* of their AS.

In terms of intelligence, those with AS (unlike those with classic autism) have an IQ within the normal range. On certain subscales of intelligence tests, those with AS have even been found to perform better than their typically developing peers (e.g. Mayes & Calhoun, 2008; Shah & Frith, 1993). They also tend to have superior attention to detail and perform better at tests involving finding images embedded within other images (Mottron et al., 2006; Shah & Frith, 1993). Indeed it has often been suggested that many successful and creative figures from history such as Wittgenstein, Einstein and Mozart may have shown characteristics of AS (e.g. Fitzgerald, 2004; Ledgin, 2002).

Baron-Cohen (2002) argues that although a range of neurological differences have been observed in those with AS, for example physically larger brains and increased cell density in some areas of the brain, this cannot necessarily be taken as evidence that this type of brain is better or worse than a typical brain. Baron-Cohen (2000, 2002) has argued that those with AS are more object-focused and oriented towards 'folk physics', whereas typically developing individuals are more likely to be people-focused and oriented towards 'folk psychology'. However, he points out that being 'object-focused' is only a disability in contexts in which people are expected to be sociable, and may actually be an advantage in certain careers such as engineering or computing (Baron-Cohen, 2002).

So what are the implications of taking context into consideration when viewing AS?

The medical and social models

The view of AS as a difference rather than a disorder is consistent with the social model of disability (Oliver, 1983). This model arose out of a series of campaigns by the Union of Physically Impaired Against Segregation (UPIAS) in the 1970s and began by emphasising the fact that people with impairments also face social

Barrier-free utopia? No meeting, communicating with, or ha... interpret other people

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problems as an additional burden. The views of UPIAS then developed further and created a clear distinction between impairments (physical limitations) and disability which was defined solely in terms of social exclusion (Shakespeare, 2006).

A dichotomy was ultimately formed between the 'medical model', which was criticised for viewing disability as an individual deficit and locating the need for change as being within the individual, versus the 'social model' which advocated acceptance of impairments and the need for society to change in order to remove the barriers which cause disability (Oliver, 2004).

The social model originated in the context of physical disabilities and was later applied to learning disabilities (e.g. Chappell et al., 2001; Walmsley, 1997). However, very little has been written on the social model of disability as applied to specifically to AS or autism.

A barrier-free utopia?

To illustrate the idea that disability does not reside within an individual but is socially constructed, Finkelstein (1981) wrote a powerful vignette about a barrier-free utopia where everything was designed and controlled by people with physical impairments. In Finkelstein's world, wheelchair users were no longer disabled by flights of steps or high kerbs, rather it was the able-bodied people who were disabled by all the low ceilings and doorways of a world designed solely for wheelchair users. However, Shakespeare (2006) points out that although 'barrier free enclaves' are possible, a world in which people with impairments are entirely free from environmental barriers is difficult to envision in reality. Considering the case of people with autism or AS, Shakespeare

(2006) suggests that 'a barrier free utopia might be a place where they did not have to meet, communicate with, or have to interpret other people'.

Others have also envisioned a similar kind of barrier-free utopia for those with AS. For example, Mark Haddon, in his novel *The Curious Incident of the Dog in the Night-time*, described how the protagonist, a teenage boy with AS, had a recurring dream in which those with autism were the only people left in the world:

> And these people are all special people like me. And they like being on their own and I hardly ever see them because they are like okapi in the jungle, which are a kind of antelope, and very shy and rare. And I can go anywhere in the world and I know that no-one is going to talk to me or touch me or ask me a question. (Haddon, 2003, p.99)

It could be argued that this complete absence of social contact would remove the disabling aspect of AS. As Attwood (2007) observes in children with AS:

> In solitude, the child does not have a qualitative impairment in social interaction. At least two people are needed for there to be a social interaction, and if the child is alone, there will be no evidence of any impairment. (Attwood, 2007, p.55)

However, in reality this would be both impractical to achieve and undesirable – it would create segregation and fail to support those with AS who strongly desire to socialise yet find this difficult to achieve. Bauminger et al. (2003) found a high incidence of loneliness in those with

What's in a name?

In this article, no distinction is drawn between Asperger's syndrome (AS) and high-functioning autism (HFA), as there has been some debate about whether it is possible to accurately differentiate between the two diagnoses. Generally, a diagnosis of AS is given where an individual meets all the criteria for HFA but has no early history of language delay. However, critics have argued that this small distinction is insufficient to warrant a separate diagnostic category (e.g. Tryon et al., 2006). In response to these criticisms, proposals are currently in place to remove the term 'Asperger's disorder' from the DSM diagnostic criteria, subsuming it instead within the more general term 'autism spectrum disorder', possibly with some modifiers to indicate severity (APA, 2010).

Although individuals across the autism spectrum may have particular strengths, the argument for autism being a difference rather than a disorder is perhaps stronger when applied to individuals with AS. As Baron-Cohen (2002) argues, those with classic autism could be said to have a disorder at least in the form of intellectual impairment, whereas those with AS have an IQ within the normal range, possess many strengths, and therefore might more appropriately be viewed as different rather than disordered. The distinct status of AS as a difference, could be cited as a reason to reject the recent proposals to place AS within the same diagnostic category as classic autism.

high-functioning autism/AS, and this would presumably only be increased in a world devoid of social interaction.

Those advocating the medical model have traditionally implied that social difficulties are a direct consequence of underlying impairments. However, one major barrier faced by individuals with AS is prejudice and discrimination. This point is made by Attwood (2002), who quotes his sister-in-law, who has AS:

> Because of the way I talk and my dislike of things that are loud, people don't always accept me or often judge me before even knowing me. If people with Asperger's find it hard to integrate into society and socialise, it

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could have a lot to do with discrimination on the part of others.

In addition to the problem of general discrimination, it could be argued that people with AS also face specific barriers in the form of inaccessible communication methods, such as unclear non-verbal signals, non-specific instructions or abstract metaphors. A possible way of reducing such barriers may be in the use of alternative methods of communication and socialisation, perhaps through greater use of computer technology.

Giving AS a voice

Computer technology and the internet have played an important role in finally giving a collective voice to individuals with AS (Bagatell, 2010). For some individuals with AS, forming campaigning groups or communities may be difficult due to the social difficulties associated with their condition. In this regard, the advent of the internet as a communication tool has been greatly beneficial in that it has allowed people with AS to form groups and therefore to claim a voice in society (Singer, 1999).

As a result of this new technology, a wide range of internet forums and chat rooms have been developed by and for individuals with AS (for example, see www.autisticadvocacy.org; www.aspiesforfreedom.com). Bagatell (2010) quotes a member of an AS self-advocacy group as saying;

> The computer is kind of like what sign language is for the Deaf. It's the autistic way of communicating. (Bagatell, 2010, p.37).

As a result of these developments, several recent studies have investigated the possibility of using computer technology to aid socialising in individuals with autism and have found that virtual-reality software can be beneficial in enabling individuals with AS or autism to practise and improve their social skills (e.g. Mitchell et al., 2007; Moore et al., 2005).

New terminology to describe autism and AS has arisen within such online communities, which often contradicts the terms used by medical professionals or parents of children with autism or AS. For example, many parents prefer 'person-first language' to acknowledge a person's humanity foremost, rather than defining the person solely in terms of his or her impairments. However, many adults with autism or AS prefer the terms 'autistic', 'Aspie' or 'Aspergic' rather than 'person with autism' or 'person with AS'. This is so as to emphasise their view that autism/AS is a fundamental part of who they are and should be seen as an acceptable 'difference', rather than as something they have which can be separated from their personhood (e.g. Sinclair, 1999, cited in Bagatell, 2010). People without autism or AS are often referred to by online autism communities as 'neurotypical' – a condition deemed to have its own relative impairments. This is demonstrated on a spoof website which features 'diagnostic criteria' for 'Neurotypical syndrome' a disorder characterised by, 'preoccupations with social concerns, delusions of superiority and obsessions with conformity' (http://isnt.autistics.org).

The online autism community is also strongly critical of those seeking a cure for autism/AS. As autism/AS is seen as a 'difference' rather than a 'disorder'; to 'cure' a person's autism would be to remove a fundamental and often positive aspect of their identity (Bagatell, 2010). However, it is important to note that this position does not necessarily represent the views of all those with autism or AS. Bagatell (2010) quotes one man as protesting strongly; 'But autism sucks! It *is* like a disease. My life sucks.' The anti-cure position has also led to conflict with some parents of children with autism or AS. Many parents acknowledge that they love their child and recognise their child's strengths yet still maintain a desire for a cure, often citing the unhappiness and frustration they see their child experiencing and the stress and disruption to family life as reasons to continue searching for this elusive cure (e.g. Schall, 2000).

Strengths of the social model

A major strength of the social model of disability is that it places moral responsibility on society to remove the barriers that individuals with AS are confronted with, rather than expecting those with AS to change in order to conform to the expectations of society. It is also a positive approach in that it acknowledges the strengths associated with AS, of which there are many (Baron-Cohen, 2002), and it is consistent with the view of AS as an acceptable difference rather than a disorder.

The social model of disability has been demonstrated to be politically effective in generating a clear agenda for social change as well as being psychologically effective in improving the self-esteem of those with impairments and building a collective identity (Shakespeare, 2006). As an approach, it is easy to understand and has clear implications for intervention. Some commonly used interventions such as TEACCH (Treatment and Education of Autistic and Related Handicapped Children) could be said to be consistent with the social model of disability. The TEACCH approach to educating children with autism or AS promotes respect for 'the culture of autism' and advocates using visual cues to structure the environment and to aid communication. Within this approach, autism/AS is accepted as a lifelong condition, and the location of intervention is in the environment (Mesibov et al., 2004). However, TEACCH is just one of a wide range of interventions commonly used with individuals with autism or AS (National Autistic Society, 2003). Advocates of the social model of

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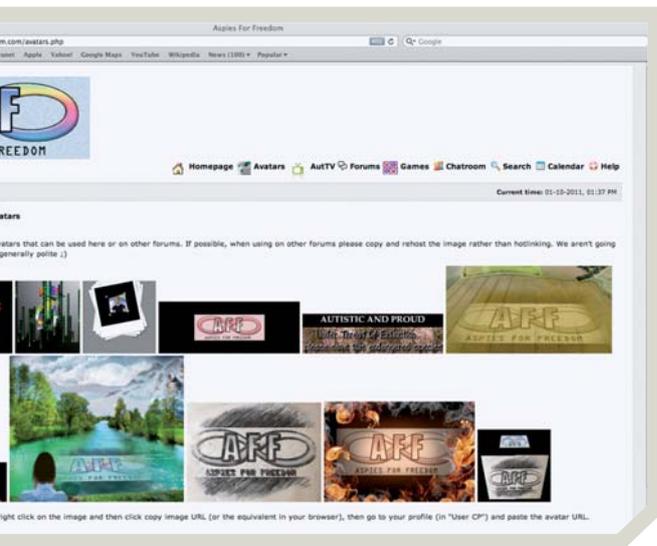
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Tryon, P., Mayes, S.D., Rhodes, R.L. &

disability would call for all potential interventions for autism to avoid trying to change the person and to focus instead on solutions that remove external barriers.

Weaknesses of the social model

The social model has arisen from political activism rather than research. It therefore has the power to inspire and to promote political change, but less power to fully explain the experiences of people with impairments. Shakespeare (2006) argues that through its exclusive focus on disability as social oppression, the social model neglects the additional role of impairment itself as a disabling factor. To apply this position to the case of AS, the traditional medical model would argue that impaired theory of mind and impaired ability to interpret non-verbal cues cause difficulties in social interaction. The social model of disability would argue that unclear communication methods and externally imposed discrimination are the cause of these difficulties. An alternative view would be that both underlying impairments and social discrimination cause social interaction difficulties for those with AS. In addition to this, it may be that discrimination exacerbates existing impairments, for example, by limiting opportunities to practise social skills, or

that discrimination creates new impairments such as depression or anxiety, which may then cause further difficulty in social interaction. To separate impairment from disability is therefore to create an artificial dichotomy that denies this complex interaction between the two concepts.

An additional weakness of the social model of disability is the problem of creating a 'barrier-free world' that is able to accommodate incompatible impairments. Shakespeare (2006, p.46) illustrates this point with the example of wheelchair users being liberated by the absence of kerbs, but blind people requiring kerbs in order to differentiate between the pavement and the road. In the case of autism and AS, this issue is further complicated by the possibility that two people who both have a diagnosis of autism or AS may have incompatible environmental requirements. For example, many individuals with autism or AS have particular sensory sensitivities and can be either hyposensitive (under-sensitive) or hypersensitive (oversensitive) to particular forms of sensory input (Bogdashina, 2003). A person with autism/AS who is hyposensitive to sounds may enjoy making loud repetitive noises in order to regulate his need for auditory input. However, this may be incompatible with the needs of another person with autism/AS who is hypersensitive to sound and requires a quiet environment.

Conclusions

In order to move beyond the current 'disorder versus difference' debate and to arrive at a consensus, it seems necessary to bridge the current divide between the traditional approaches to AS and the social model of disability and to consider whether the two positions are necessarily

mutually exclusive. The reality of the impairments associated with AS is widely acknowledged, and it is accepted that well-being may be impacted upon directly by impairments, for example by extreme sensory sensitivities. However, it is also widely acknowledged that many of the barriers faced by people with AS arise from society rather than from the individual. For example, one in five children with autism/AS have been excluded from school and 40 per cent of children with autism/AS have been bullied by their peers (Batten et al., 2006). As adults, only 15 per cent of those with autism/AS are in full-time employment and over 70 per cent of those who live on their own have been bullied or harassed (Rosenblatt, 2008).

In seems likely that rather than the experiences of those with AS being directly caused by their neurology, as the medical model has been much criticised for implying, or being entirely socially constructed, as strict interpretations of the social model would argue, there is an interaction between impairment and social environment. There is currently no 'cure' for the impairments of AS, and many people in the autism community are offended by the suggestion that AS should be cured, given its associated strengths and its inseparability from a person's identity. Therefore, it seems that the greatest potential for intervention is located in the social environment, and this is also where the moral imperative for change lies. In accordance with the Disability Discrimination Act 2005, reasonable adjustments should be made to accommodate those with AS in society. These adjustments could be through alterations to the environment to avoid sensory overload, through the use of clear visual communication methods (e.g. TEACCH), or through the use of computer technology, such as the internet or virtual reality environments, to aid communication (Mitchell et al., 2007; Moore et al., 2005). Rather than aiming to change individuals with AS, we 'neurotypicals' have a responsibility to try to see the world through the eyes of those with AS and to reduce the social barriers that contribute to their disability. After all, we are the ones without any empathy difficulties, aren't we?

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