

The Social Construction of Asperger Syndrome: the pathologising of difference?

HARVEY MOLLOY¹ & LATIKA VASIL²

¹The National University of Singapore, 10 Kent Ridge Crescent, Singapore 119260, and ²Nanyang Technological University, Nanyang Avenue, Singapore 639798

ABSTRACT *This article poses the question 'Is Asperger Syndrome (AS) a disorder or a neurological difference that has been socially constructed as a disorder?' AS is currently defined within the medical paradigm as a developmental disorder. Alternative conceptualisations of Asperger Syndrome have largely been absent within the academic discourse on AS. Drawing on the emerging field of disability studies we examine how the diagnostic category of AS has been socially constructed. Our contention is that Asperger Syndrome has been readily adopted as a category because of its value as a category of special education. In other words, the school is a pivotal institution in the dissemination of AS as a category. Within the framework of special needs AS is viewed as a social disability and the aim of professional interventions is to help to rehabilitate or 'normalise' the child. In attempting to re-frame this conceptualisation of AS it is important to shift the emphasis from issues of diagnosis and evaluation to examining the social implications of representing children as having AS.*

This article critically explores the complex issues surrounding the diagnosis of Asperger Syndrome. To date Asperger Syndrome has been defined within the medical/psychiatric classificatory paradigm as a disorder, thus largely falling within a deficit model. Alternative conceptualisations or re-framings of Asperger Syndrome have largely been absent within the academic discourse on AS. As the linchpin of this discussion we pose the question: is AS a disorder or a neurological difference that has been socially constructed as a disorder? Fundamental then to this discussion is an examination of how AS has been socially constructed, in particular emphasising the role of schooling and special education in this social construction.

What is Asperger Syndrome?

Asperger Syndrome is a relatively new diagnostic classification that defines a childhood behavioural and neurological disorder. In 1994 following international field trials (Volkmar *et al.*, 1994) it was included for the first time in the DSM-IV (American Psychiatric Association, 1994) under the umbrella category of Pervasive

Developmental Disorders (PDD). Pervasive Developmental Disorders describe all disorders, including autistic disorder, in which there is a qualitative impairment in the development of reciprocal social interaction, communication and imagination. Thus, Asperger Syndrome emerged as a separate diagnostic category from autism. It is currently viewed as a variant of autism or sub-category of autistic spectrum disorder and a Pervasive Developmental Disorder (Atwood, 1998). Due to its recent emergence there is at present very little known about Asperger Syndrome, particularly its epidemiology and etiology.

The origins of AS can be traced back to the work of a Viennese pediatrician, Hans Asperger, who published a paper based on the clinical observations of a small number of boys referred to his clinic for educational problems in 1944. These children had normal intelligence and language development, but exhibited significant deficits in social and communication skills. Asperger used the term 'autistic psychopathy' to describe this pattern of symptoms. The term Asperger Syndrome first appeared in Wing (1981) who presented a detailed account of the main clinical features of the syndrome based on 34 case studies of children and adults whose characteristics were similar to those originally described by Asperger. While Asperger's work was first published in English in 1979 it only began to receive greater attention in the 1990s when it was published in Uta Frith's book *Autism and Asperger Syndrome* (1991).

The DSM-IV criteria for a diagnosis of AS, using similar terminology to that of the diagnostic criteria for autism, includes the presence of qualitative impairment in social interaction (e.g. failure to develop age-appropriate peer relationships) and restricted, repetitive, and stereotyped patterns of behaviour, interests and activities involving preoccupation with one or more stereotyped and restricted pattern of interest, inflexible adherence to specific non-functional routines and rituals, stereotyped or repetitive motor mannerisms, or preoccupation with parts of objects. These behaviour patterns must be sufficient to interfere significantly with social or other areas of functioning. Furthermore, there must be no significant delay in general cognitive function, self-help/adaptive skills, interest in the environment or overall language development. Other clinicians have developed more specific diagnostic criteria based on those described in the DSM-IV (e.g. Gillberg & Gillberg, 1989). The main clinical features of Asperger Syndrome include:

- lack of empathy;
- naïve, inappropriate, one-sided interaction;
- little ability to form and sustain friendships;
- pedantic, repetitive speech;
- poor non-verbal communication;
- intense interest in certain subjects;
- clumsy and ill-coordinated movements and odd posture (Atwood, 1998).

Issues and debates in the diagnosis of Asperger Syndrome

Within the medical classificatory approach to AS there have been several issues or areas of contention in terms of the diagnosis and evaluation of AS. First, there is the

more general issue that the medical model approach to developmental disorders is largely counter-productive; the basis for this criticism being that once children are labelled they tend to be defined by their diagnosis thereby losing their individuality and limiting other people's expectations of them. Once a diagnostic label is attached there is the risk that all the child's characteristics are filtered through this diagnosis or explanatory mechanism resulting in a tendency to view the child's behaviour as symptoms, rather than as expressions of his or her unique personality. Furthermore, by ascribing to this perspective the source of the 'disability' is firmly located within the individual and not as a result of the expectations of the social contexts in which the individual exists. However, on a more pragmatic note, diagnostic categories are useful in terms of providing a structure for research (Bishop, 1989) and for individuals to gain access to support and resources.

Another issue in the diagnosis of Asperger Syndrome is variability in the interpretation of diagnostic criteria—in other words what behaviour constitutes necessary diagnostic features? (Bishop, 1989). While the DSM-IV definition now provides a frame of reference for the diagnosis of AS there still remain shades of gray based on variability in interpreting the absence or presence of some features and the severity of these. Wing (1981) noted:

As with any condition identifiable only from a pattern of abnormal behaviour, each element of which can occur in varying degrees of severity, it is possible to find people on the borderlines of Asperger Syndrome in whom diagnosis is particularly difficult. Whereas the typical case can be recognized with ease by those with experience in the field, in practice it is found that the syndrome shades into eccentric normality, and into certain other clinical pictures (p. 120).

Frith (1991) displayed concern over the fuzziness of diagnostic criteria: 'Does it make sense to talk about deficits and exclusive categories? Should one instead talk about normal and abnormal behaviour shading into each other? To put it another way, should one look at Asperger Syndrome as a normal personality variant?' (p. 23). What is at stake then in how we construct AS is what we consider to fall within the category of 'normal behaviour'.

A related issue is the problem of establishing diagnostic boundaries. As Asperger Syndrome shares characteristics with diagnostic categories emerging from other fields (e.g. non-verbal learning disabilities syndrome from neuro-psychology, dysfunction in sensory integration from occupational therapy) there has been some diagnostic confusion resulting in varying and multiple diagnoses. Singer (1998) makes a similar point noting that in clinical practice there is even little consensus as to the name, with the same pattern of symptoms being referred to as Asperger Syndrome, High Functioning Autism and Autistic Spectrum disorder, to name a few.

A further issue in the diagnosis of AS within the medical paradigm is that the clinical presentation of AS changes with age. The DSM-IV definition is of the condition as it appears in early childhood. As the child develops, some diagnostic criteria may no longer be met and, thus, the definition may no longer be of

diagnostic value. The question remains then what utility does the diagnostic category have for older individuals? In summary then, the diagnostic classification of AS within the medical paradigm remains problematic within its own frame of reference.

The Social Construction of Asperger Syndrome

The medical approach has largely dominated the discourse on Asperger Syndrome. At present, the condition is posited as a neurologically based impairment or disorder, located within the individual and that is primarily treated by rehabilitative therapies. Its recent inclusion in the DSM-IV as a Pervasive Developmental Disorder confirms its status as a medical pathology in terms of present cultural designations. Alternative perspectives of AS have largely been absent from discussions of the condition as have analyses of the social construction of the category.

In this article we wish to explore some of these issues. In particular, we question whether AS constitutes an actual impairment as opposed to a neurological difference and we examine how AS has been socially constructed. In exploring these issues we wish to draw links between the recent work in the field of disability studies and the growing body of literature on AS. Disability studies is an emerging interdisciplinary academic field that critically explores issues related to the inter-connections between disability and cultural contexts. The field of disability studies involves critical inquiry into the representations and constructions of disability along with political advocacy using theoretical models from the social sciences and the humanities. Disability studies can inform educational practice by advocating a thorough analysis of the social constructions of disability and the role of cultural institutions, such as schools, in these constructions.

The field of disability studies began with the formulation and discussion of the social model of disability (Oliver, 1990). This model challenges the medical model's view that disability is caused by physical entities that exist in the world, and instead posits disability as an interpretation of physical differences by discourses invested by social and political power. The implication of the medical model is that all illness and disability, including mental 'illness', is caused by biochemical changes and the fundamental agent shaping human experience is the biological constitution of the body. This logic suggests that disability could be eradicated if we could develop treatments for all illnesses and impairments. The medical model posits disabilities and illnesses requiring medical treatment that exist independently from how they are viewed and classified by medical discourses. The social model of disability also agrees that impairments and illnesses exist in the world, but acknowledges that how these illnesses and impairments are classified, treated and interpreted is socially constructed.

The social model makes a crucial distinction between impairment and disability, first articulated in the UPIAS 'Fundamental Principles' document:

Impairment—lacking part of or all of a limb, or having a defective limb organisation or mechanism of the body.

Disability—the disadvantage or restriction of activity caused by a contem-

porary social organization which takes no account of people who have physical impairments and thus excludes them from mainstream social activities. (UPIAS, 1976, quoted in Goodley, 2001, p. 208)

Impairments, such as the inability to hear, exist in the world, but deafness, as a disability, is socially constructed. To clarify the social model, Marks (1999) provides the example of race: 'Social model theorists would argue that impairment has no more relevance to the topic of disability than the study of sex organs has to the study of gender, or the study of skin colour has to the study of 'race' (Marks, 1999, p. 59). Sexual and racial differences exist, but differences in skin colour or sex organs tell us nothing about the social mechanisms of racism and sexism. The questioning of the ontological status of a disability is common within the field of disability studies and originates, in part, from the modes of inquiry initiated by French post-structuralist thought in the 1960s, specifically the work of Foucault (1991); work later developed into the field of discourse analysis (Fairclough, 1992). Just as Foucault's project was born in the milieu of French student activism for curriculum and social change in the mid-1960s, the social model of disability was co-emergent with the formation and growth of advocacy groups who viewed themselves as engaged in a political struggle against a hostile society that constructed them as disabled subjects. The social model served as a powerful political weapon that challenged the hegemonic power of medical discourse: disability no longer resided in the individual, but was rather a multi-determined product of a diverse range of discourses and social practices including medical discourses, architectural and town planning practices, school assessments and the like.

Recently, a second wave of writing in disability studies has examined some of the key assumptions of the social model of disability (e.g. Corker & French, 1998; Hughes & Paterson, 1997). These critiques have largely focused on the problematic split, inherent in social model theory, between impairment and disability. For example, Corker and French (1998) argue that 'because the distinction between disability and impairment is presented as a dualism or dichotomy—one part of which (disability) tends to be valorized and the other part (impairment) marginalized or silenced—social model theory, itself, produces and embodies distinctions of value and power' (p. 2). Thus, the split is viewed as problematic because it ignores or denigrates the lived experience of the body and consigns impairment to the domain of medical discourse and authority (Hughes & Paterson, 1997). The second wave writers refocus attention onto impairment in an attempt to redress the abandonment of the body that is the legacy of the social model. Goodley (2001, p. 208) argues that 'rather than viewing a turn to impairment as depoliticising, re-medicalising and "watering down" the social model' this turn is part of a re-socialisation of impairment that allows for accounts of both the lived experience of impairment and the ways that impairment is discursively embodied. The turn to impairment is part of a political strategy of re-writing impairment outside medical discourse without recourse to personal tragedy narratives; as such while it questions the consignment of the body implicit in the social model, it nevertheless shares many of the political aspirations of early writers in disability studies.

The various approaches to theorising about disability can be plotted on an axis from a totally 'realist' materialist position (medical) to a totally socially constructed position (post-structuralist). In this way, the axis allows us to chart and plot the authoritative knowledge claims made by certain discourses that attempt to describe the reality of AS. The DSM-IV, for example, operates solely according to the medical model: there is no acknowledgement of the history of AS as a medical condition or of the role played by those doing the labeling in creating and shaping the condition. It is as if AS always existed in the world until the DSM-IV discovered the exact elements that combine to define or characterise the syndrome. The inclusion of a diagnostic category in the DSM-IV gives a particular definition an 'official' status, while masking the fact that a clear consensus may not exist, as we have previously highlighted in the case of Asperger Syndrome. At stake in the nuances of these theoretical dilemmas is the question of how we understand AS outside of the hegemony of medical authority and discourse. What is striking about the majority of professional literature to date on Asperger Syndrome is the unwillingness to confront the fundamental philosophical question posed by the development of the category of AS. Does AS define a condition that exists 'out there' in a reality that is beyond language and the network of social and political forces involved in the process of defining normal and abnormal behaviour?

Let us return to our original question: Is AS an impairment, as described in the DSM-IV, or a difference? Goodley's (2000) work on learning difficulties and the social model of disability is pertinent to this question. Noting that learning difficulties problematises the UPIAS definition of impairment, Goodley proposes that:

The social model represents impairment as opposite in character to disability, the former not being seen as socially produced (Hughes & Paterson 1997, p. 329). At this stage, in conceptualizing the impairment of people with learning difficulties, two available options can be identified. The first involves an acceptance of 'learning difficulties' as having some organic basis, but arguing that people with such an impairment should not be excluded and their difference should be celebrated. The second option—one strongly proposed by Paul Abberley in 1987—involves questioning the naturalized notion of impairment. The 'difference' of people with learning difficulties, understood as being located in some biological deficit, individualizes their very humanity: ripping them out of a social context, placing them within the realms of pathological curiosity (p. 35).

Goodley's reflection on the politics of situating the origin of learning difficulties points to the problems and stakes in deciding between a difference and an impairment. While AS children need and often demand more attention than other children, and while these children display scant regard for social norms can we really speak confidently of a social impairment that is located solely within the child? To speak of a social impairment in this way implies that there is a clearly demarcated spectrum of normal social behaviour into which all childhood behaviour confidently falls and that a failure to correspond to this norm constitutes an impairment. A

parent of a child obsessed with Thomas the Tank Engine, bus timetables or astronomy would agree that such obsessions are tiresome—but if the child matures into a world expert on the Kuiper Belt then it is difficult to see how an obsessive interest is in itself a disability. Many children with AS have poor motor skills and often require occupational therapy to develop the necessary skills to be able to hold a pen in order to write. Yet anecdotal evidence suggests that these children frequently excel at computing and are often quick to learn keyboard skills. Goodley concludes his consideration of the two options of conceptualising learning difficulties by declaring that ‘while we can accept that people with learning difficulties do themselves recognize that they may be “impaired” and “different” ... the social model of disability can only include people with learning difficulties when it recognizes the social origins of “learning difficulties” and “difference”’ (Goodley, 2000, pp. 35–36). Goodley’s observation applies to any application of the social model of disability on those either diagnosed as having AS or those who identify themselves as having AS. Our contention is that AS is never simply located within the individual: no gene or discovery of different neurological ‘wiring’ arrangements will wholly explain AS.

Given that the status of AS as a diagnostic category is subject to a radical questioning, how then has it been constructed as a syndrome worthy of being listed in the DSM-IV? What are the specific forces and mechanisms at work in the social construction of AS? What conditions and influences led schools, health and education professionals to adopt the term and identify children as having Asperger Syndrome?

To map the social construction of a disability, we need to pose the question asked by Sleeter (1986) in her examination of the social construction of learning disabilities: ‘Why did the category come about in the first place, and whose interests has it served?’ (p. 47). Our contention is that Asperger Syndrome has been readily adopted as a category because of its value as a category of special education. In other words, the school and in particular special education services are pivotal in the dissemination of AS as a category. It is worth noting here that an acceptance of the medical model approach to disability is implicit in the field of special education. Key assumptions in special education are that disability is a pathological condition that students have, diagnosis is an objective and useful practice, and special education is considered to be a rationally conceived and coordinated system of services for the benefit of diagnosed students (Bogdan & Kugelmass, 1984). A child’s poor performance in school is thus due to some problem within him or her and not as a result of educational practices. In an argument that has many implications for understanding the role of schools in the construction of AS, Dudley-Marling and Dippo (1995) contend that ‘learning disabilities rhetoric may be about difference, but learning disabilities practice, which stresses (a) adaptive behavior; (b) coping strategies; and (c) right (i.e., normal) ways of thinking ... talking, and interacting, has the effect of “normalizing” students’ while leaving unchallenged conventional notions of what is normal or natural’ (p. 410). It is interesting to note that in the case of Asperger Syndrome anecdotal evidence would suggest that the majority of diagnoses of AS are precipitated by the child entering an educational setting, be it preschool or school.

This raises the issue of the situational nature of disability in general and AS in particular. A child with AS who is obsessed with astronomy and is able to pursue and advance this specialisation with a private tutor is less likely to have as many problems or to appear as aberrant as the same child placed in a mass general education classroom.

It is also worth commenting that the rise of AS as a category occurs at a time when there is a new set of relations between school and special education providers (such as speech therapists, educational psychologists and occupational therapists). AS emerges as a diagnostic category in the late 80s/early 90s exactly when in many countries the school and special education services were undergoing a profound transformation from centralised state-funded and run institutions to more autonomous institutions that liaise and contract the service of special education services. If we apply the tools of discourse analysis (Fairclough, 1992; Dudley-Marling & Dippo, 1995) we can uncover the tacit assumptions behind the various formulations of AS and the AS child's 'needs'. AS emerges within a network of new relationships where the parent or school (as client) negotiates—and purchases—the services of a range of autonomous professionals such as a support teacher, speech therapist, occupational therapist and educational psychologist. The school's duty in this new set of relationships is not only to educate children but to identify children with special needs and to work with parents to contract the special education services most suited for that child. Rather than posit social construction as a single, architectonic formation that interprets an impairment or neurological difference, it is more accurate to speak of competing social constructions of AS. A speech therapist specialising in autism may belong to a professional body that favours a particular approach and interpretation of AS that differs from that of an OT working in sensory integration or a neurologist with a special interest in brain and nervous system functioning. Within this network of relations, AS functions as a convenient common category that allows each of the individual parties to communicate with one another about the peculiarities of the child's personality, behaviour, learning achievements and needs.

What each of these separate though related professionals share is a language and rhetoric centred on the child's *needs*. As each professional (e.g. speech therapist, occupational therapist, teacher) articulates and frames their understanding of the AS child with a range of interpretative tools and in a discourse common to their profession, their exchanges reinforce the assumption that AS child has special needs that must be catered for and accommodated if s/he is not to be swallowed by the education system. The common rhetoric of the child's needs conflates a range of different needs: the need of the school to maintain order and to function smoothly; the needs of the parents to make sense of their child's behaviour; the needs of the speech therapist and occupational therapist to have a common methodology and concomitant professional language to support their practice. Given that many parents of children with AS face anxieties about accommodating their child into a mainstream school, we should accept that the term Asperger Syndrome functions as a *de facto* educational category. In many cases, parents receive the diagnosis of AS from special education services contracted to the school. The diagnosis of AS in

such an institutional framework clearly blurs the distinctions between the needs of the child, parents and the school: especially as a diagnosis of AS may result in the school being able to apply for funding to receive special educational resources. The notion of 'the child's needs' divorced from the needs of the school to maintain order and discipline has already been questioned with regard to the category of 'Emotional and Behavioural Difficulties' (Thomas & Glenny, 2000). We propose that a similar questioning of 'needs' be conducted for the *de facto* educational category of Asperger Syndrome.

Within the framework of special needs AS is viewed as an individual pathology and the aim of therapies and professional interventions is to help to rehabilitate or 'normalise' the child. The child is now viewed not as an eccentric, sometimes naughty child, but as a lifelong sufferer of AS. In this way, the category of AS effectively reduces the range of behaviour patterns that would count as 'normal', though eccentric, and sentences the child to a lifetime of special needs and interventions.

Beyond Deficit: re-framings of Asperger Syndrome

In attempting to re-frame the current medical conceptualisation of AS, it is important to shift the emphasis from the usual concerns of refining diagnosis and evaluation (i.e. how can we better identify those with Asperger Syndrome) to examining the social repercussions of representing children as having AS. In doing so, we begin to address issues of representation and power. For example, we may begin to ask whose knowledge and definitions are being represented in the research descriptions of AS and whether these representations are contestable. In this vein Danforth (1995) and Thomas and Glenny (2000) critically examine the education of children labelled emotionally disturbed. They suggest that within the field of special education, research and theoretical accounts of the psychological defectiveness of children labelled emotionally disturbed have been accepted as an incontestable truth resulting in the placement of standardised and devalued identities upon their lives. Once these children have been labelled as emotionally disturbed, there is little opportunity for them to contest, in a public arena, the validity of this label. Similarly, within the academic discourse on emotional and behavioural disturbance the voices of those who have been labelled are rarely incorporated into this accepted body of knowledge. Danforth makes the important point that 'research and practice have effectively defined individual lives under the pathology heading without addressing the politics of knowledge, without allowing for significant personal meanings of those categorized persons (the persons we serve) to be valued as knowledge' (p. 138). Similar claims can be made in the case of children identified as having Asperger Syndrome.

While Danforth's claims about the nature of the special education knowledge base are valid it is worth noting that in recent years the dominance of the logical-positivist paradigm of knowledge in the social sciences has been challenged by post-positivist social scientists resulting in a growing acceptance of non-objectivist methods of research and analysis. Within disability studies and special education,

objectivist quantitative approaches no longer completely dominate the scholarship in the field. Increasingly, interpretative research and narrative inquiry is finding a place in the special education knowledge base (Ferguson *et al.*, 1992).

Danforth notes that, while the children themselves do not understand or have access to the powerful academic discourse on emotional disturbance, they do resist the ways in which their lives and behaviour have been pathologised. In the case of children labelled as having Asperger Syndrome, we have little knowledge of the personal understandings of the very children we are categorising or the social repercussions of being labelled for these children. While adult personal accounts of AS are emerging (e.g. Willey, 1999) they are largely outside of the academic theorising on the condition and therefore have little impact on special educational practices that are usually informed by academic theory and research. These personal accounts are written by individuals who have voluntarily adopted the label of AS as adults based on their own recollections of their 'symptoms' as children. We do not know what effect the *involuntary* labelling of a child as having AS has on the quality of that child's life. In other words, to date, our labelling of children as having Asperger Syndrome is uncontested. For these children an integral part of their childhood will be learning that they bear the label of AS, and coming to terms with the fact that they are perceived as having a personal pathology or disability.

We would argue that academic scholarship and, consequently, educational practice in the area of AS, and more broadly special education, must go beyond a deficit perspective, and incorporate and legitimise the experiences and understandings of the children that we are labelling. For example, do these children perceive themselves as having a disability? Willey (1999) in her book *Pretending to be Normal* charts her childhood experiences and her eventual discovery of the diagnostic category of AS as an adult. She concludes: '... no matter what the hardships, I do not wish for a cure to Asperger's Syndrome. What I wish for, is for a cure for the common ill that pervades too many lives; the ill that makes people compare themselves to a normal that is measured in terms of perfect and absolute standards, most of which are impossible for anyone to reach' (p. 121).

It is likely that, once the medical construction of Asperger Syndrome is challenged by alternative models of disability, individuals labelled with this condition will become more politicised, and play a more central and active role in shaping our cultural definitions of AS. This may result in a shift away from a purely rehabilitative therapeutic approach to one that places at its centre the strengths associated with the condition and acknowledges the role of society and its institutions, in particular educational institutions, in framing its weaknesses. At present, the Internet would appear to be the locus of an emerging body of knowledge on Asperger Syndrome authored primarily by those identified as having AS. These web sites challenge the medical model approach to defining AS as a pathology, instead re-positioning the condition as a valid and even interesting difference from the neurological norm. Often a focus of these writings is the identification of gifted historical and present day celebrities reputed to have AS (e.g. Einstein, Wittgenstein)—the logic being that if AS is a disability it would appear to have many strengths associated with it.

It is likely that the labelling of children as having AS will be increasingly contested as scholarship in the field is challenged into addressing the issues of the power dynamics involved in and the social repercussions of such labeling with its implications of deficit and pathology. Such challenges, however, will only occur if we continue to critically examine diagnostic labels such as Asperger Syndrome in terms of how they are contextualised in our culture as opposed to viewing them as personal pathologies.

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