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Why psychiatrists do and do not define ‘me’: the dropping of Asperger Syndrome from the Diagnostic and Statistical Manual of Mental Disorders (DSM)

Posted by [Mike Talkaboutautism](#) at [Monday, July 08, 2013](#)

By Damian E M Milton

Introduction

“However the APA [American Psychiatric Association] defines autism, the diagnosis is going to be imprecise. That’s the nature of a spectrum...Unfortunately, I don’t think the latest effort — the DSM-5 — is going to be much help in clearing up the confusion, and in some ways, it’s only going to complicate the situation.” ([Grandin, 2013](#)).

In recent months there has been much furore concerning the publication of the latest version of the Diagnostic and Statistical Manual of Mental Disorders ([DSM-V, 2013](#)), published by the American Psychiatric Association. The latest edition of this manual, which aims to provide criteria by which mental disorder is classified, has included a number of changes to how the ‘autism spectrum’ is now to be defined. The terms Asperger Syndrome and PDD-NOS have been dropped to be replaced by Autism Spectrum Disorder (ASD) and Social Communication Disorder (practically ‘autism’ without the associated ‘repetitive interests’). In the new definition of ASD, social interaction difficulties have been subsumed within the category of social communication, whilst sensory processing differences have appeared, but have been subsumed within the category of repetitive and restrictive behaviours. Diagnosis will also be seen in terms of ‘severity’.

So, why would an autistic ‘activist’ such as me be concerned with this change in terminology? Unlike others, I do not feel robbed of some essential descriptor of who ‘I’ am. I have never been a champion of the functional deficit model of autism (or its being applied to neurodiversity more widely) espoused by the DSM, or for that matter the International Statistical Classification of Mental and Behavioural Disorders ([ICD-10, 1992](#)), the diagnostic tool that was used to classify ‘me’ as ‘having Asperger Syndrome’. The reason I care is due to how these changes will affect how others perceive ‘me’, and others who are autistic, and what social service support may be deemed necessary. Also, having a diagnosis is a social tool, a piece of ‘cultural capital’ ([Bourdieu, 1986](#)), a ‘technology of self’ ([Foucault, 1972, 1973](#)), that can be used by both psychiatrist and ‘patient’. Thus, a change in the way autism is defined is as the Sociologist [C. Wright Mills \(1959\)](#) would have said: a public issue and not just an individual’s personal problem.

Moving the goalposts: DSM and its critics

The initial DSM was published in 1952 and evolved out of a number of systems for collecting data, from psychiatric hospital statistics, and a manual produced for the US Army. The first two editions listed far fewer ailments than later editions and included some references to psychoanalytic ideas as well as behaviourist interpretations. Following critiques from radical psychiatrists such as R.D. Laing, Thomas Szasz, and David Cooper (names that still automatically get many a psychiatrist into some kind of 'defence mode'), and the embarrassment that led on from the studies completed by David [Rosenhan \(1973\)](#) which undermined the validity of psychiatric assessments, the DSM-III was released in 1980. This edition sought to standardise diagnostic criteria upon the best available evidence, yet has remained a controversial document ever since. For instance 'Sexual Orientation Disturbance' was not removed until 1987 and the DSM-III-R publication.

As recently argued by [Insel \(2013\)](#) of the National Institute of Mental Health (NIMH) in the US in criticism of the new DSM-V, categorisations within it are generally made by looking at clusters of symptoms/behaviours, rather than underlying causation:

"While DSM has been described as a "Bible" for the field, it is, at best, a dictionary, creating a set of labels and defining each."

Yet, for conditions that have multiple interweaving developmental variables affecting how biological factors manifest themselves in lived experience, if a biological basis cannot be found, what then? [Insel \(2013\)](#) is right to point out the lack of validity in categorisations made of the basis of symptoms; yet when does a brain/mind become 'biologically disordered'? This will always be socially situated and interpreted. Unlike [Insel \(2013\)](#), I do not contend that an 'eliminative materialist' philosophy of mind (the idea that the mind/consciousness will be explained by scientific investigation) is fully possible. Yet indications can be made to correlate subjective data with findings regarding neurology, but this will need varying subject disciplines and 'stakeholders' to work together, something rarely done at present.

Some psychiatrists of a more radical tradition argue that rather than maintaining a categorical system for defining mental distress, what is needed is a dimensional or complaint-based approach ([Bentall, 2004](#); [Cooper, 2004](#); [Krueger et al. 2005](#); [Timini et al. 2011](#)). A recent report from the Division of Clinical Psychologists of the British Psychological Society ([BPS, 2013](#)) suggests that current systems of categorisation do not take into account to what extent a disorder is produced due to internal biological factors, and how much is due to psychological responses to environmental conditions. An issue that remains for these critics however, is to answer the question: if one removes the label, how would one decide who should have access to support services and on what basis?

The DSM and autistic self-identity

Even when looking at autism from the 'inside-out' (Grandin, 2013; Williams, 1996), defining what autism 'is', is no simple task, with some arguing that deficits in social interaction and communication are central to the autistic difference, with the primary research priority being neurobiological (Grandin, 2013), and others arguing that differences in cognition lead to differences in sociality, interactions, and shared understandings with others (Lawson, 2008, 2010; Murray et al. 2005; Milton 2012a; Milton 2012b). The former argument would have more in common with Insel's (2013) criticisms, whilst the latter would share with the BPS (2013) the pressing need to take into account biological, psychological, and social factors and how such factors intersect in the lives of people within changing contexts.

Whatever the cognitive difference is, one also has to think – different to what exactly? The DSM, as with much psychological and psychiatric theory, is based on notions of deviance from a measured normative state of affairs. Whilst idealising functional normative efficiency may be needed when looking at engineering for example, it can leave a lot to be desired when applied as a way of thinking to the subjective lived experiences of human beings (Bentall, 2004). Whilst some may feel that acquiring a diagnosis of autism has helped to explain their difficulties in life, for me they have helped to explain how certain others have come to see people 'like me' through a kind of psychologising 'gaze'. Thankfully I'd say, I'd personally built up my own theories of dispositional diversity and an already 'othered' self-identity before ever coming across such descriptions of the autistic difference. Thus, although I found diagnosis useful in many ways, I did not internalise its meanings as defining who 'I' am.

Many years ago, the social theorist George Herbert Mead (1934) distinguished between the socially defined 'me' (how others see me) and the subjectively (but also socially derived) 'I' (how I see myself). Later, psychologists like Erikson (1975) argued that a disjuncture between the two led to various stages of 'identity crisis' as someone moves through the lifespan. Somewhat associated with this, Goffman (1963) suggested a gap between the 'social me as perceived' and the 'social me as expected' led to social stigma. Becker (1963) also suggested that negative associations attached to labels can become internalised into how people see themselves in a 'self-fulfilling prophecy'. Thus, identifying with the 'disordered other' as described by psychiatrists leads (in my view), to occupying a self-defeating position. Yet, reclaiming the autistic 'I' from such descriptions, will be 'swimming against the tide' of powerful groups and individuals that may stigmatise you for it.

For me, identity, as Edley (cited in Hollway, 2007) argues, is like a 'jelly that never sets'. Yes, my 'I' identifies as being 'autistic', and that 'I' shares a common social label with many other people, and within the wider autistic community I have felt camaraderie and recognition. I have also come across great differences in terms of how people define themselves with regard to such labels. So, will the removal of Asperger Syndrome from the DSM alter the cultural map? Yes, already it has caused quite a stir. Will it remove the term completely from the cultural lexicon? I very much doubt it. Perhaps the term/meme will just take on a slightly differing guise, as in 'high-functioning autism', or 'mild autism' (both equally poor descriptors too). Also, the removal of the term Asperger, being a man's surname, describing someone's condition/identity should please some autistic feminists, of which I have met quite a few.

As we move forward in these debates, it is nigh-on impossible to accurately predict how these changes will impact in a cultural sense, yet I for one am pleased to see academics in the field move beyond the classification systems of yesteryear. This should hopefully lead to more interesting and informative research. Yet a question we should all be asking is: what is needed in terms of clinical practice? Diagnosis of autism at present is clearly flawed, but post-diagnostic support is often even more so. Many people are dependent on such definitions to identify with, to access support and services (however ill-equipped). When so few people diagnosed as autistic have secure employment, housing, educational opportunities and so forth, a removal of the system altogether would cause even greater harm if there was not something better to replace it. In order for such a system to come to fruition, it will need the subject and practitioner 'silo's' ([Arnold, 2010](#)) to start to communicate and work with one another, and that includes autistic people themselves!