

## WHEN ASPERGER'S DISORDER CAME OUT

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### SUMMARY

**Background:** In 2013, the American Psychiatric Association removed Asperger's Disorder from the DSM, offering instead the new DSM-5 diagnosis: Autism Spectrum Disorder. This change has been hailed the most controversial exclusion from the DSM, yet unlike the 1973 removal of homosexuality from DSM-III, Asperger's disorder has not been demedicalised. Rather, the disorder has simply been reclassified as part of the DSM-5 Autism Spectrum and therefore retains its fundamental characteristic as a mental disorder owing to its inclusion within the sphere of the DSM.

**Methods:** This paper is based on a review of the current academic literature in conjunction with careful reading of the DSM-5.

**Results:** Removing the Asperger's label, valued by patients for its distinctiveness from autism brings with it the potential to inflict iatrogenic harm.

**Discussion:** This paper demonstrates how the DSM-5 reclassification has the potential to threaten the identity of those affected, and discusses the problem of autism as a stigmatizing diagnostic label.

**Conclusions:** A case is made for the use of tandem social/colloquial – medical/technical terminology to refer to the conditions classified under DSM-5 Autism Spectrum Disorder, in order to square the circle of social concerns regarding identity and stigma with the need for diagnostic clarity to continue to advance medical practice.

**Key words:** autism - Asperger's - DSM-5 - stigma

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### INTRODUCTION

'Don't let us Aspies lose our identity' pleaded responses to an online survey for members of the UK autism community in the wake of changes to the DSM-5 diagnostic criteria for neurodevelopmental disorders (Kenny et al. 2016). Through this, it became clear that – among the survey respondents at least - 'many people with Asperger's like their distinct diagnosis (since) it looks quite different from autism' (Kenny et al. 2016). Yet a diagnosis of Asperger's disorder is no longer available under the DSM-5 classification system. Instead, the 'new DSM-5 disorder' Autism Spectrum Disorder is offered, subsuming the previously separate conditions autism, Asperger's disorder, childhood disintegrative disorder, etc. in order to improve diagnostic accuracy (American Psychiatric Association, 2013).

Particularly in the context of Asperger's disorder, this change has been hailed 'the most controversial exclusion from DSM-5' (Cooper 2014). However, unlike the 1973 removal of homosexuality from DSM-III, Asperger's disorder has not been demedicalised. Rather, the disorder has simply been reclassified as part of the DSM-5 Autism Spectrum and therefore retains its fundamental characteristic as a mental disorder owing to its inclusion within the sphere of the DSM – a document so powerful each new edition brings a fresh opportunity to advance psychiatry and 'improve the way patients are cared for' (Kupfer et al. 2013). Yet removing the Asperger's label, valued by patients for its distinctiveness from autism, brings with it the potential to inflict iatrogenic harm. At the level of affected individuals, the Asperger's diagnosis was declared 'central to their identity' (Spillers et al, 2014). Not only does the DSM-5

reclassification threaten individual identity, but with drawing the discrete Asperger's disorder also risks endangering the sense of 'groupness' afforded by an official diagnosis to the Aspie subculture (Ben-Zeev et al. 2010). Furthermore, concerns over losing both diagnosis and identity are compounded by fears of exchanging the 'palatable' Asperger's disorder for the highly stigmatized alternative label, autism (Gensler 2012). In light of this, a case shall be made for the use of tandem social/colloquial – medical/technical terminology to refer to the conditions classified under DSM-5 Autism Spectrum Disorder, in order to square the circle of social concerns regarding identity and stigma with the need for diagnostic clarity to continue to advance medical practice.

### BACKGROUND

To remove a disorder from the DSM classification system is to swim against the tide of the current trend in psychiatry, given that the development and addition of new disorders has 'caused concern about expansion of the concept of mental illness' (Boysen 2011). It might be expected, then, that removing Asperger's from DSM-5 would be met favorably, in light of the double challenge of both symptoms and stigma associated with mental disorders in society (Corrigan & Watson 2002). However, a distinction must be made between entirely removing a disorder from the DSM and reclassifying a disorder such that individuals simply transfer between two labels both diagnostic of mental pathology.

Homosexuality was removed from DSM-III in 1973 following the 1969 Stonewall riots orchestrated by gay rights activists who held that the establishment of psychiatric theories of homosexuality, leading ultima-

tely to its inclusion in the DSM, was 'a major contributor to anti-homosexual social stigma' (Drescher 2015). It was determined that homosexuality did not in fact meet the criteria for a mental disorder, given that such disorders 'all regularly cause subjective distress or generalized impairment in social functioning', yet 'many homosexuals experience no distress or disability' (Spitzer 1987).

This change was welcomed as a major victory both by the gay community and its allies, bringing an end to the 'desperate attempts to become who they could not be, and love whom they could not love, all in the name of getting well' (Greenberg 2013). There was no further usage of the homosexuality classification of mental disorder, and nor was there a replacement diagnostic term for homosexuality in subsequent editions of the DSM. However, the original terms lesbian, gay, bisexual and so on continued to be widely used both by members of the gay community and society at large, given that such terms are not considered to be stigmatizing. Rather, there are regular Pride parades: 'loud, colorful, and joyful celebrations of LGBT identity' facilitated at least in part by the demedicalisation of homosexuality (Bruce 2016).

Interestingly, the symbolism of the rainbow flag is not confined to demonstrations of LGBT pride and diversity. It has also been taken up by the neurodiversity movement to demonstrate the 'rainbow of intelligences' displayed by those exhibiting what would be described under the biomedical model as atypical neurological development (Armstrong 2011). In celebrating the full range of 'normal human difference', neurodiversity activists reject the inclusion of the Autism Spectrum as a psychopathology in the DSM at all (Jaarsma & Welin 2012). As seen with the dawn of gay rights activism in the 1970s, with neurodiversity comes a degree of pride in, for example, identifying as 'being Asperger's' (Kenny et al. 2016). As a result, the movement considers classifying neurodevelopmental differences as DSM mental disorders to 'disrespect... their natural way of being' (Jaarsma & Welin 2012).

## METHODS

### A Close Reading of the DSM-5

Despite the apparent similarities between the rainbow-hued gay pride and neurodiversity movements, demedicalisation of neurodevelopmental disorders has not gained majority support from the affected communities. Rather, DSM-IV Asperger's and DSM-5 Autism Spectrum Disorders have been described as disabling conditions, explained in terms of 'dysfunction against norms of society and expectations' (Kenny et al. 2016). Indeed, the 'clinically significant' impairment in social effectiveness and functioning that the DSM-5 sets out as being a key component of the Autism Spectrum cements the validity of its classification as a mental disorder (American Psychological Association 2013).

## RESULTS

### Asperger's – In or Out?

The removal of Asperger's Disorder from DSM-5 cannot be understood as equating to its demedicalisation. In fact, those with a 'well-established DSM-IV diagnosis of Asperger's disorder' would find themselves to be newly diagnosed according to the replacement DSM-5 classification of Autism Spectrum Disorder with further qualifications to indicate its severity, rather than without a diagnosis at all (American Psychological Association 2013). Under the DSM-5 classification system, an individual meeting the criteria for a DSM-IV diagnosis of Asperger's disorder would instead be assigned the label Level 1 Autism Spectrum Disorder, without accompanying language or intellectual impairment (American Psychological Association 2013, Tobia & Toma 2015).

Moreover, it has been suggested that it is actually 'unlikely or impossible' for the DSM-IV diagnosis of Asperger's disorder to exist as a disorder distinct from autism (Mayes et al. 2001). The rationale behind subsuming Asperger's disorder into the DSM-5 Autism Spectrum Disorder was therefore not to reduce the incidence of Asperger's disorder, but that it was required because 'the distinctions between Asperger's, autism and related conditions imposed by the DSM-IV could not be reliably drawn' (Cooper 2014). In short, moving away from separate neurodevelopmental disorders while continuing to include the same characteristics required to be exhibited in order to meet the criteria for diagnosis therefore means that most children with DSM-IV diagnoses will still meet the DSM-5 criteria and as such be placed at an appropriate point along the autism spectrum (Cooper 2014).

## DISCUSSION

### When Asperger's Disorder Came Out

Accordingly, it has been argued that the practical consequences of the changes to the diagnostic criteria for neurodevelopmental disorders in the DSM-5 actually 'does not represent a stark departure from current practice', in the sense that they remain diagnosable conditions of variable severity (Esler & Ruble 2005). Despite this, research has suggested subsuming the Asperger's label into DSM-5 Autism Spectrum disorder will 'have major social implications' (Gensler 2012).

While it would appear that it is a purely linguistic move to separate Asperger's disorder from autism at large, there have been calls for the term Asperger's in particular to be 'kept in the language' (Cooper 2014). It is argued here that this is largely due to the centrality of the term in the Aspie subculture and identity, which draws sharp distinctions between those diagnosed with Asperger's Disorder and autistic people in general on an individual and community basis.

In the first instance, removing the label Asperger's disorder could have a profound impact on the many people who consider the diagnosis to be a central part of their identity, with some going so far as to describe themselves as 'I am Asperger's' (Kenny et al. 2016). As such, it is unsurprising that individuals have expressed their unwillingness to dispose of their Asperger's diagnosis in line with the new DSM-5 classification of Autism Spectrum Disorder. Indeed, surveys of the autism community revealed it was felt that care needs to be taken in distinguishing between the conditions, rather than treating Asperger's and autism as interchangeable 'when they are not' (Kenny et al. 2016).

The resistance to an umbrella classification arises at least in part from the value affected individuals place upon employing the Asperger's label as a succinct method to communicate about those 'whose difficulties were less severe than those with the straight diagnosis of autism' (Martin, 2013). In short, it would appear that those diagnosed with DSM-IV Asperger's disorder self-identify as being different from the autistic community at large and that the removal of the separate label from the DSM-5 threatens to 'lump... Asperger's and autism together' (Linton et al. 2014).

Identity is further generated through a sense of belonging to a group. Given that Ben-Zeev et al. (2010) credit the application of a diagnostic label with classifying a person into a group, it follows that in the case of Asperger's disorder, to re-classify an individual under the DSM-5 Autism Spectrum is to automatically place them in an alternative group. In addition to resistance on the grounds of threats to personal identity therefore comes the collective resistance expressed by the Aspie subculture, which largely developed through the Internet and other forms of electronic communication, connecting those specifically with an Asperger's diagnosis for support and solidarity (Vasil & Molloy 2004).

While the criteria presented in DSM-5 for the classification of autism spectrum disorder continues to separate the diagnosis into disabilities of varying severity as it did in DSM-IV, concerns about autistic homogeneity have been raised by those who identify with the linguistically distinct Asperger's label and associated Aspie subculture. For the individual identifying as an Aspie, erasing the term Asperger's from the DSM has potentially a twofold effect: not only is his individual Asperger's label replaced by the previously distinct autism, but his social group within the Aspie subculture is under threat. To remove Asperger's disorder from DSM-5 is to do the 'unthinkable' (Spillers et al. 2014). It is to delegitimize the identity and culture of this social group and thus represents a 'real trigger for concern' (Jaarsma & Welin 2012).

The reluctance of the Aspie subculture to accept the new DSM-5 terminology also speaks volumes about the negative social perceptions of autism (Linton et al, 2014). A number of survey respondents, as well as voicing personal affront over the loss of part of their identity, went on to broaden their evaluation of the

changes in DSM-5 by considering the potential impact upon the general public, stating that they also 'find it confuses people that Asperger's is part of ASD and reduces the understanding of the severity of classic autism' (Kenny et al. 2016). Indeed, it is widely believed that individuals with diagnoses of autism and Asperger's disorders have 'different functioning levels' (Linton et al. 2014). Therefore in emphasizing the higher level of disability held to be associated with autism, such responses illustrate the desire of the Aspie subculture to maintain a distinct Asperger's diagnosis in order to retain its current perception as a 'lesser' impairment than autism (Kenny et al. 2016).

Implicit in the pleas for the retention of an Asperger's disorder label distinct from the DSM-5 Autism Spectrum Disorder is the fear of social stigma, which is unfortunately often attached to the psychiatric disorders defined in the DSM. The surveys conducted by Kenny et al. (2016) captured both concerns about potential social stigma for those with a DSM-IV Asperger's diagnosis who would be replacing it with DSM-5 Autism Spectrum Disorder, as well as the lived experiences of the wider autistic community. Put simply, parents generally expressed a preference for a diagnosis of Asperger's disorder for their child since it was perceived to carry less social stigma than autism, neatly evidenced by the experience of a parent who said: "If I tell people he [my son] has ASD they look at me with pity and he is excluded from mainstream clubs and friends; if I say he is Asperger's people nod approvingly' (Kenny et al. 2016). It therefore follows that even those individuals with DSM-IV High Functioning Autism, now reclassified with DSM-IV Asperger's Disorder under the shared label of DSM-5 Autism Spectrum Disorder Level 1 Severity, have been reported as experiencing considerable 'courtesy stigma' as a consequence of their association with a stigmatized group, in this case the autism community (Gray 2002).

The impact of the combination of erasing a label upon which many have, perhaps even proudly, constructed both their personal and collective sub-cultural identities, and replacing it with diagnostic terminology associated with significant social stigma, has been characterized as presenting a significant risk for psychological and identity crises in those who previously identified with Aspie subculture (Jaarsma & Welin 2012). As a result, it is argued here that the revisions made in the interest of medical clarity in DSM-5 risk inflicting iatrogenic stress, and consequent psychological trauma, upon those who would be forced not only to adopt terminology at odds with their sense of identity but to engage with newfound social stigma, in a direct violation of the Hippocratic principle *primum non nocere*, which governs the medical establishment: the oath to first, do no harm.

Of course, a possible solution to the substantial objections to the DSM-5 classification of neurodevelopmental disorders might be simply to reinstate the DSM-IV classification Asperger's disorder; a diagnosis pre-

ferred 'because it [does] not immediately equate with mental illness' and therefore the associated social stigma (Spillers et al. 2014). However, to do so would be to ignore the plight of those remaining within the stigmatized autism spectrum.

Attempts to address the socially entrenched stigma against autism and thus the all-encompassing DSM-5 Autism Spectrum Disorder are reminiscent of the efforts of physical disability charity The Spastics Society, which rebranded as Scope (Rye 2012). Its previous nomenclature caused grave concern for those affected by conditions like cerebral palsy, since the term spastic had increasingly become a term of 'playground abuse' (Rye 2012). In fact, many parents of children with cerebral palsy reported through surveys that they had chosen not to seek the support services of The Spastics Society to avoid their children being associated with the stigmatizing label (Rye 2012).

Extrapolating from such responses, The Spastics Society came to understand that using such terminology undermined the aims and efforts of the charity to challenge prejudice against those with visible disabilities, given the social stigma that came with being labeled in this manner (Rye 2012). It was felt that 'most important is the reaction of those with cerebral palsy' and thus the Society became Scope in 1994 in accordance with the popular members' vote against being identified as spastic (Rye 2012).

It was suggested by Smith (2013) that the charity name change to Scope likely influenced the phenomenon whereby the word 'spastic has been largely erased from popular English usage'. Removing the 'legitimizing effect and prominence' of the word spastic from the name of such a large national charity 'must surely have contributed' to this effect, and in so doing progress was made towards stigma reduction – a key aim of the charity Scope (Rye 2012).

The example of Scope demonstrates the power of the terminology used to name or describe a given condition, both in terms of how those affected identify with the label, and the potential to create or eradicate attached stigma. Similar sentiments have been expressed in relation to autism, too. In summary, it is held that the 'language we use has the power to reflect and shape people's perceptions of autism' (Kenny et al. 2016).

## CONCLUSIONS

I shall therefore conclude by offering two possible alternatives to the total removal of the Asperger's disorder label seen in DSM-5, with the aims of preventing potential iatrogenic harm by maintaining the 'helpful diagnosis' identified with by members of the Aspie subculture, while addressing the wider problem of social stigma demonstrated to be associated with DSM-5 Autism Spectrum Disorder (Cooper 2014).

One approach, suggested by Ben-Zeev et al. (2010), is to change the name of DSM-5 Autism Spectrum Disorder such that it is 'not anchored in the most severe

of the disorders on the continuum'. Employing this strategy leads to the alternative label Asperger's Spectrum Disorder, which shifts the focus toward a 'lesser' and non-stigmatized diagnosis (Kenny et al. 2016). Retaining a spectrum mirrors the objectives of the DSM-5 revisions to create an autistic continuum to enhance diagnostic accuracy rather than relying on linguistic divisions (American Psychological Association 2013). However, it is possible that Asperger's Spectrum Disorder would also be rejected by members of the Aspie subculture wishing to retain their distinct 'groupness', on the grounds that members of a given group are likely to be overgeneralized as homogenous by society at large (Ashton & Esses 1999).

In light of these tensions, it has been suggested that the terms used in the DSM 'should be what people on the spectrum want', implying that – as seen with Scope acting on its members' wishes – 'you should attach most weight to the views of people with autism or Asperger's' (Kenny et al. 2016). Therefore, combining accepted social or colloquial terms like Asperger's with the medically preferred technical DSM-5 terminology Autistic Spectrum Disorder might well offer a solution.

Under this tandem system, competing diagnostic labels would merge to become Asperger's (Autism Spectrum Disorder, Level 1 Severity). This enables the retention of a distinct 'Aspie' identity while drawing this neurodevelopmental disorder closer to the DSM-5 Autism Spectrum, a move designed to reduce overall social stigma such that those affected might go on to share the level of pride in their identity as that expressed by the gay community.

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