



Upcoming changes to autism spectrum disorder: evaluating DSM-5



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What is autism spectrum disorder (ASD)? The most candid answer to this question is: ‘we do not know – yet’. An extensive research endeavor is underway to identify the ASD ‘disease entity’ or biomarker: the underlying abnormalities of brain development, structure and function that constitute the disorder itself. To date, this work has not yielded a consensus; autism is an enigma that has thus far stubbornly resisted description, let alone explanation.

This presents a practical and theoretical problem. We do not know what ASD actually is and we cannot observe or assess it directly. Nevertheless, in order to understand and help people with ASD, clinicians, researchers, educationalists and other stakeholders need to be able to identify the disorder. This bind is not unique to ASD. In fact, it is almost universal to the study and treatment of psychopathology.

The best solution to the problem posed by the lack of a biomarker for ASD is to make educated guesses about how it manifests. These educated guesses, written down in the DSM and the International Classification of Disease, are called diagnostic

criteria. As such, diagnostic criteria for ASD are a sort of working hypothesis, that a particular cluster of symptoms signifies the presence of the disorder. Like all hypotheses, diagnostic criteria need to be tested against data and modified accordingly.

With the publication of DSM-5 in May this year [101], the international consensus about how ASD manifests, and how it can be identified, has been rewritten. In the move from the fourth to the fifth edition of the DSM there has been a profound shift in the conceptualization of ASD that will have ramifications for research and clinical practice. In this editorial, I seek to describe and evaluate four key changes to diagnostic criteria, and to offer some thoughts on their likely implications.

Triad to dyad

The pioneering work of Wing, Gould and Rutter resulted in a longstanding and widely accepted notion about ASD: that it manifests as a triad of related but distinct impairments [1,2]. In DSM-IV these symptom clusters were called ‘impairments in social interaction’, ‘impairments

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in communication' and 'restricted, repetitive and stereotyped behavior' (RRSB) [3]. The architects of DSM-5 have chosen to do away with the venerable autistic triad, and to replace it with a dyad, comprising 'social-communication' and RRSB symptom dimensions.

This decision to merge the social and communication domains of the autism triad is well founded, and is a genuine example of diagnostic criteria being modified for strong scientific reasons. Subsequent to the publication of DSM-IV, the accrual of large data sets collected using standardized measures, and advances in computing that have made multivariate statistical techniques increasingly accessible, have allowed for the DSM-IV model of autistic symptoms to be tested empirically. Diverse factor analytic studies have found the triadic model to be an inferior description of autistic symptoms compared with the DSM-5 dyadic model [4-6]. These findings initially informed, and then vindicated, the decision-making of DSM-5's architects.

Sensory abnormalities as a core feature of ASD

When I talk to people with ASD, and read their accounts of having ASD, they often convey that unusual sensory experiences are a profoundly important feature of their lived experience. One friend with ASD recently told me about giving a talk to 150 senior professionals, and the challenge that arose, not due to social anxiety, but from being in a room with an intricate and colorfully patterned carpet. Despite the prominence of sensory abnormalities (SA) within autistic phenomenology, they have received relatively little attention from researchers over the years. This may reflect the fact that SA's were not considered by DSM-IV to be a key feature of ASD. By contrast, DSM-5 has listed as a core, diagnostic symptom of RRSB "hyper- or hypo-reactivity to sensory input or unusual interest in sensory aspects of environment; (such as apparent indifference to pain/heat/cold, adverse response to specific sounds or textures, excessive smelling or touching of objects, fascination with lights or spinning objects)."

As with the move from the triad to the dyad, this decision to include SA in diagnostic criteria is well founded upon the scientific literature. Crucially, there is evidence that SA is a good indicator of whether a person has ASD. It is sensitive (i.e., found in most people with ASD) and some types of SA are reasonably specific (i.e., not found

in most people without ASD) [7]. Furthermore, factor analytic evidence suggests that SA fits comfortably into the RRSB dimension of the ASD dyad, as hypothesized by DSM-5 [4]. In addition to these scientific justifications, there is something sensible and respectful about including such a key element of the phenomenology of ASD in official diagnostic guidelines. Hopefully this will stimulate the interest of researchers to understand better the features and causes of abnormal sensory processing in ASD.

Lumping of ASD

Darwin once observed that in the design of a taxonomy there will be tension between 'lumping' and 'splitting' [8]. Lumping involves emphasizing the similarities between phenomena and classifying them in broad inclusive categories. Splitting, by contrast, is driven by a focus on differences, and results in complex classification systems with multiple taxa. DSM-IV was dominated by a splitting tendency, but in DSM-5 it is the lumpers who have been most influential. This is exemplified by the shift in diagnostic criteria for ASD. Under DSM-IV conventions, there were several related but distinct ASD subtypes (or 'pervasive developmental disorders'). These subtypes included autistic and Asperger's disorders, with the later being diagnosed when a child had autistic social, communication and RRSB impairments in the absence of significant language delay. In DSM-5 these distinctions have disappeared, with all autistic subtypes being lumped into a single ASD diagnostic category. Thus, DSM-5 has abolished Asperger's disorder.

Once again, it is difficult to fault the science behind this modification of diagnostic criteria. On current evidence, there is no convincing argument to be made that autism and Asperger's disorder are meaningfully distinct entities that require separate labels. People with these disorders show many more similarities than differences, and there is little to suggest that they diverge in terms of etiology, treatment needs or prognosis [9]. Furthermore, clinicians are unable to distinguish between DSM-IV ASD subtypes with any consistency [10].

At this point, I would like to make a controversial suggestion: that scientific criteria should not provide the only measure of a diagnostic system. When considering the merit of a diagnosis, it is right that there should be a concern with its validity (or 'trueness'). However, we should also consider the utility of that diagnosis, namely its usefulness to a range of stakeholders (patients,

clinicians and administrators among others) within the cultural, social and economic context in which the diagnosis is given. What else is DSM-5 for than to be useful to patients [11]?

While the DSM-IV distinction between autism and Asperger's disorder almost certainly lacked validity, it probably did have some utility. Clinical experience and some preliminary empirical evidence suggest that many young people and their parents feel more comfortable with an Asperger's diagnosis [11]. Adults with Asperger's are sometimes fiercely proud of their label and its distinction from autism. This probably reflects the fact that in our culture there is more stigma attached to autism, whereas the lay public often hold positive stereotypes about people with Asperger's. In abolishing Asperger's for sound scientific reasons, DSM-5 has cast aside a valuable way of labeling the autistic difficulties of some verbal, intelligent people, which manages to emphasize strengths as well as difficulties. It will be interesting to see how the term 'Asperger's disorder' persists in our culture, despite its removal from official nosology.

Will DSM-5 make ASD rarer?

By changing the rules for diagnosing ASD, there is a risk that the threshold for diagnosis will change, and with it the prevalence of ASD. DSM-IV listed 12 symptoms of autistic disorder, requiring that a person have six or more of these, with at least two in the social domain and at least one in each of the communication and RRSB parts of the triad. A DSM-IV pervasive developmental disorder not otherwise specified diagnosis could be attained with just three symptoms, with no requirement that these span the full autism triad. By contrast, for a DSM-5 ASD diagnosis, a person must have all three social-communication symptoms, and fulfil at least two of the four RRSB criteria. It has been pointed out that there were 2027 ways to meet DSM-IV criteria for ASD, but only 11 in DSM-5 [102].

These changes have raised concerns that the bar for an ASD diagnosis has been raised by DSM-5, and that many people who would previously have met criteria will now be excluded from the autistic spectrum. Various research groups have attempted to test this prediction by applying DSM-5 criteria in extant data sets, and examining the overlap between those meeting DSM-IV and DSM-5 criteria. One study, using data from the DSM-IV field trial, caused a panic

that spilled over into the pages of the mainstream media by suggesting that 40% of those with a DSM-IV diagnosis would not meet DSM-5 ASD criteria. Of particular concern was the finding that 75% of those with Asperger's disorder and 72% with pervasive developmental disorder not otherwise specified would be excluded from the autism spectrum by DSM-5 [12]. Others have also come to the conclusion that DSM-5 ASD lacks sensitivity [13].

In the face of this evidence, the American Psychiatric Association's Neurodevelopmental Disorders Work Group have staunchly defended their DSM-5 ASD diagnostic criteria. They point out that old datasets simply do not contain sufficient information to estimate properly a DSM-5 diagnosis, and argue that this methodological problem has artificially depressed the sensitivity of their diagnostic criteria [14]. One of the architects of the DSM-5 criteria has, with colleagues, recently published an influential study, based on an enormous, well-characterized sample, suggesting that there is no sensitivity problem for DSM-5. Surprisingly, this work raised a different concern, that DSM-5 criteria may lack specificity leading to overdiagnosis of ASD [15].

On the basis of currently available evidence, it is simply not possible to know what impact DSM-5 will have on prevalence rates for ASD. If there has been an alteration of the diagnostic threshold this could have serious implications. It would risk rendering obsolete the huge body of literature on DSM-IV ASD by limiting its generalizability; and might exclude individuals with significant neurodevelopmental problems from receiving a diagnosis and the support that comes with it. Clarity on this matter must be achieved quickly, based on independent studies using measures that can accurately implement DSM-5 criteria.

Resistance to change

Many people with ASD feel uncomfortable with change, and this appears to extend to ASD researchers and clinicians too. The arrival of DSM-5 has engendered much anxiety. I argue that this is largely unfounded. Diagnostic criteria should evolve as they are tested against data. The changes to ASD in DSM-5 are largely empirically driven and, as such, have resulted in more valid criteria than in DSM-IV. In particular, DSM-5 offers a more accurate picture of the nature and structure of autistic symptoms. Nevertheless, the question of whether the threshold

for diagnosis has been substantially altered remains unanswered, and urgent research efforts are required to resolve this.

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