Diagnosing Autism Spectrum Disorder: who will get a DSM-5 diagnosis?

The moment when a child or adult is given a formal diagnosis of autism can be a life-changing moment for an entire family. Clinical teams involved in diagnosis are guided in the process of making this important decision by a set of international guidelines which classify psychiatric conditions. These guidelines, called the Diagnostic and Statistical Manual of Mental Disorders (DSM), change every five to ten years or so, and the new edition, DSM-5 was published earlier this week. The drafts of the proposed criteria released prior to publication led to much concern and controversy. One major concern was that many individuals, particularly those with higher ability could miss out from getting a diagnosis. New research results published in the Journal of Child Psychology and Psychiatry and carried out by an international team led by Cardiff University’s Wales Autism Research Centre will help to clarify this issue.

What is changing that has been creating a concern? The diagnostic description for autism used to include the presence of symptoms in three main areas; 1) social interaction, 2) communication and 3) restricted-repetitive behaviours and interests. The new DSM-5 descriptions replaced these with just two symptom domains: 1) social-communication behaviours, and 2) restricted-repetitive behaviours. The new definition is called “Autism Spectrum Disorder (ASD)“.

Although the changes have come about because research findings indicate the need for a more inclusive ‘spectrum’ description, many people are concerned about whether these new criteria will exclude some individuals who would currently receive an autism diagnosis. This is especially the case because the new single description called Autism Spectrum Disorder replaces the previous separate descriptions of subgroups such as Asperger syndrome and PDD-NOS. Individuals who have higher ability are often those who have these subgroup labels.

The research team, led by Cardiff University, included researchers from Newcastle University, Leiden University (the Netherlands) and KU Leuven (Belgium), and the UK National Autistic Society. The team used a standardised diagnostic tool called the Diagnostic Interview for Social and Communication Disorders (DISCO) and compared several different techniques to test the DSM-5 criteria. The analysis was carried out at several levels including testing both the main criteria and also the sub-criteria that contribute to the diagnosis. This detailed analysis enabled the researchers to compare their findings with other studies and to examine the new diagnosis in children and adults of different ability levels.

The study highlighted the importance of comparing techniques that researchers and clinicians use to measure diagnostic criteria, indicating why some other research studies using the DSM-5 criteria had found the DSM-5 under-diagnosed while others found the criteria over-diagnosed. Importantly, the results showed that using the appropriate techniques, the DSM-5 criteria correctly identified people who should receive a diagnosis of ASD across age and ability. In particular, individuals with higher ability were unlikely to be missed with the new DSM-5 ASD description.

The study may therefore help to reassure individuals and families about concerns surrounding the publication of DSM-5. However, a more stringent test of the new DSM-5 criteria is needed as clinicians begin to apply the new criteria. This should include a large sample of individuals referred for assessment through standard clinical care pathways and should include a larger sample of girls and women. In conclusion with the arrival of the new DSM-5 criteria we still seem to be caught pitfall of diagnostic labelling, with the ongoing challenge to reconsider and change our approach to diagnosing the spectrum of autism conditions.

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