



ORIGINAL ARTICLE

Towards the *DSM-5* Criteria for Autism: Clinical, Cultural, and Research Implications

Giacomo Vivanti, Kristelle Hudry, David Trembath, Josephine Barbaro, Amanda Richdale and Cheryl Dissanayake

Olga Tennison Autism Research Centre, School of Psychological Science, La Trobe University

The new edition of the *DSM* is proposing significant changes to current diagnostic definitions of autism and related conditions. In this article, we will discuss the clinical, research, and cultural implications of these changes. We conclude that the new criteria appear to better reflect current understanding of the autism spectrum disorder than the current *DSM-IV* criteria. As expected with any major change in classification systems, there are also significant risks, which will have to be carefully monitored and addressed by both policy makers and the scientific community to ensure that best clinical practice and research are facilitated and advanced.

Key words: Asperger's disorder, autism, *DSM-5*, ICD, social communication disorder.

What is already known on this topic

- 1 Autism and related conditions cannot be diagnosed using medical tests. Therefore, diagnosis of these complex disorders still relies on behavioural features defined by classification systems such as the *DSM* (American Psychiatric Association) and the International Classification of Diseases (ICD; World Health Organization).
- 2 Since the publication of the current diagnostic definition of autism and related conditions in the *DSM-IV* (1994), an unprecedented amount of research has been undertaken to investigate the nature and developmental course of these disorders.
- 3 The knowledge generated by this research has led the *DSM* committee to propose significant changes in the diagnostic definition of autism and related conditions in the next edition of the *DSM*, scheduled to be published in March 2013.

What this paper adds

- 1 Analysis of the potential implications of the new diagnostic definition suggests that the *DSM-5* diagnostic criteria have the potential to simplify the diagnostic process and increase diagnostic reliability.
- 2 However, it is possible that some individuals who currently meet criteria for autism or related conditions will no longer meet criteria under the new *DSM-5* diagnostic definition.
- 3 Another risk is that the next edition of the ICD will not conform to the new *DSM-5* criteria, thus jeopardising the international consensus about diagnostic criteria.

Almost two decades after the publication of the *DSM-IV* criteria, the new edition of the *DSM*, scheduled to be published in 2013, is proposing significant changes to current diagnostic definitions of autism and related conditions. Some of these changes are of a controversial nature and concerns have been raised by the scientific community (McPartland, Reichow, & Volkmar, 2012; Rutter, 2011; Wing, Gould, & Gillberg, 2011) and by major advocacy groups (e.g., Autism Speaks, Asperger Services Australia, UK National Autistic Society). In particular, with the introduction of the new diagnostic criteria, some of the diag-

nostic concepts that have crucially influenced clinical practice, research studies, and cultural perceptions of autism will no longer be used, most notably the concepts of "Asperger's disorder," "pervasive developmental disorders," and the "triad of symptoms." The purpose of this position article is to summarise the proposed changes and to consider their possible clinical, research, and cultural implications.

Main Differences between *DSM-IV* and *DSM-5*

The proposed criteria for the *DSM-5* involve one central diagnosis—autism spectrum disorder (ASD)—that will replace the different subtypes defined by the *DSM-IV* (autistic disorder, Asperger's disorder, childhood disintegrative disorder, and pervasive developmental disorder—not otherwise specified (PDD-NOS)). The diagnosis of Rett syndrome will no longer be included in the *DSM*. The ASD diagnosis will be accompanied by

Correspondence: Giacomo Vivanti, Olga Tennison Autism Research Centre, School of Psychological Science, La Trobe University, Bundoora Campus, Melbourne, VIC 3086, Australia. Fax: +61 3 9479 1956; email: g.vivanti@latrobe.edu.au

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the indication of the level of symptom severity (on a 3-point scale ranging from “requiring support” to “requiring very substantial support”) as well as relevant clinical “specifiers,” including language and cognitive ability levels.

Social and communication problems will be melded into one category, “social/communication deficits,” which, together with “fixated interests and repetitive behaviours,” will replace the traditional triad of symptoms (impaired social reciprocity, impaired language/communication, and restricted and repetitive pattern of interests/activities) that has been in use since autism (childhood autism) first found a home in *DSM-III*. Language impairment/delay is not listed as a relevant feature for the diagnosis of ASD.

Unusual sensitivity to sensory stimuli, a clinical feature of autism that was not listed in the previous criteria, will now be included as a specification of the behaviours that can be coded in the “fixated interests and repetitive behaviours” domain.

The diagnostic criterion of onset before 36 months is replaced with a more “open” definition, stating that “Symptoms must be present in early childhood, but may not become fully manifest until social demands exceed limited capacities.”

The *DSM-5* will also introduce a new diagnostic label within the category of Language Impairments; “Social Communication Disorder.” This diagnosis appears to be quite similar to that of ASD, as individuals diagnosed with social communication disorder should have an “impairment of pragmatics” and impairment in the “social uses of verbal and nonverbal communication.” However, there are two key factors that will differentiate children diagnosed with ASD and those diagnosed with social communication disorder. First, children with social communication disorder must have “persistent difficulties in pragmatics and or the social use of verbal and non-verbal communication in natural contexts, which affect the development of social reciprocity and social relationships” that cannot be explained by children having difficulties with their language skills (e.g., word structure and grammar) or intellectual disability. Therefore, a child presenting with broad language difficulties (not just in the area of pragmatics) or cognitive delay is unlikely to meet the first criteria for social communication disorder. Second, the presence of fixated interests and repetitive behaviours is an exclusionary criterion for social communication disorder. Therefore, the presence of repetitive behaviours will be crucial for the differential diagnosis of ASD.

Finally, with the new diagnostic procedures, if the child presents with additional symptoms that are sufficient to meet criteria for other disorders, then he or she will be diagnosed as having two or more disorders (e.g., ASD + ADHD). This was not possible under *DSM-IV*.

Clinical Implications

Twenty years after the introduction of the *DSM-IV* criteria, there are still questions regarding the validity of the non-autism *DSM-IV* subtypes (Asperger’s disorder, childhood disintegrative disorder, and PDD-NOS) as separate and distinct from autistic disorder. Longitudinal research has documented that distinctions among these subtypes is inconsistent over time (e.g., a child might meet criteria for autistic disorder at age 3 and PDD-NOS at age 5; Daniels et al., 2011). Moreover, reliability in

the application of diagnostic subtypes was documented to be poor across sites (e.g., the same child could be diagnosed as having Asperger’s disorder at one site and autistic disorder at another site; Lord et al., 2012), and numerous studies reported little or no qualitative differences between these groups (see Macintosh & Dissanayake, 2004, for a review). These findings, together with data suggesting common genetic risk factors for the different subtypes, have led to the decision to combine these diagnostic categories. Therefore, it is possible that the diagnostic process using *DSM-5* will be “simplified,” as clinicians will no longer need to spend resources to determine what specific subtype of autism a child has. This change might help with a more timely diagnosis, thereby getting children into treatment more quickly.

Nevertheless, concerns have been raised as to whether the diversity and heterogeneity of ASD can be adequately captured if subtypes no longer exist. For example, with the introduction of the proposed *DSM-5* criteria, a child with Asperger’s disorder who has an above-average IQ and a circumscribed interest in the French Revolution would receive the same diagnosis as a non-verbal child who spends his days spinning objects and flapping his hands. However, the *DSM-5* guidelines address this issue by employing a more descriptive approach that involves accompanying the ASD diagnosis with the indication of relevant clinical features such as the level of symptom severity and associated verbal and cognitive abilities. Therefore, instead of a diagnosis of Asperger’s disorder, the child may receive one of “ASD with good language skills and high intelligence, requiring support for his social communication and requiring very substantial support for his repetitive behaviour.”

There are also concerns about the fact that the new definition will narrow the criteria for ASD, so that people who currently meet the criteria for a *DSM-IV* subtype may no longer meet criteria for an ASD according to *DSM-5*. This might be especially relevant for individuals with milder characteristics of autism (e.g., individuals with Asperger’s disorder, PDD-NOS), as highlighted in a recent study by McPartland et al. (2012). However, results from the first *DSM-5* field trial suggest that only 5–10% of people currently captured within the pervasive developmental disorders spectrum will no longer meet criteria for ASD. Many of them (possibly those who do not present with obvious repetitive behaviour) might now be classified in the new category of “Social Communication Disorder” (Swedo, 2012).

By bringing social and communication skills together under one category and eliminating any reference to verbal communication, the proposed criteria focus less on when, and to what extent, a child has developed language, and more on how he or she communicates to initiate and maintain social interactions. This change might lead to earlier diagnoses for those children who do not show delays in language development, as is the case for many people who currently meet criteria for Asperger’s disorder. These individuals are typically identified later than those presenting with delays in language development (as is the case for many who meet criteria for autistic disorder).

In terms of treatment, in the 20 years that have passed since the introduction of the *DSM-IV* criteria, there is no evidence that the type of intervention advocated should be based on an ASD “subtype.” Therefore, there is no reason to anticipate problems with treatment following a move to *DSM-5*. Clinical

research indicates that treatment goals and strategies should be planned on the basis of the individual's profile of strength and weakness rather than on his or her particular diagnostic label, and this will not be affected by the proposed changes (National Research Council, 2001). Nevertheless, the elimination of *DSM-IV* subtypes has the potential to impact access to services. For example, in the USA, some state legislations (e.g., California) and insurance policies allow access to services only to children diagnosed with autistic disorder. It is not known how such policies will change in response to the new criteria. One possibility is that funding will be tied to the severity ratings proposed in *DSM-5*, whereby individuals "requiring very substantial support" would have greater access to support services. While not foreshadowed, such a change will have the potential to place additional pressure on clinicians responsible for diagnosing ASD to lean towards more severe ratings in the interests of ensuring access to those in need of services. Nevertheless, this pressure exists already under the *DSM-IV* criteria, reflecting health economics issues rather than the validity of the diagnostic criteria. Irrespective of the approach taken, it is very unlikely that access to services will be simply extended to anyone with an ASD diagnosis and, of more concern, to those who meet criteria for social communication disorder.

In Australia, it has been the case that support has been variously tied to the diagnostic label of autistic disorder versus Asperger's disorder with differences across states and across services despite funding mechanisms (e.g., funding for teachers' aids, carer payments) needing to be tied to an individual's level of disability/functioning regardless of their diagnosis. Therefore, it is possible, although again not foreshadowed, that such criteria could be expanded to include the proposed severity ratings. Irrespective of the approach governments take in accommodating the proposed changes, it is imperative that they ensure that the introduction of the new criteria will not result in changes in coverage policies that will exclude people with ASD from access to services (Lord & Jones, 2012).

Research Implications

Through its characterisation of ASD as a heterogeneous group of conditions, the *DSM-IV* has stimulated tremendous research into the different types of ASD. The new criteria, which will replace five diagnostic labels with a single label, fail to emphasise the notion of "multiple conditions" within the spectrum. This can be viewed as a significant limitation for research, as future studies may necessarily focus on one "entity" (i.e., ASD) rather than multiple. However, research in the last decade has raised many questions about subtype boundaries, showing that the symptoms of autistic disorder, Asperger's disorder, and PDD-NOS are more similar than different, while the severity and relevance of the symptoms varies between but also within diagnostic subtypes (e.g., Fernell et al., 2010). The dimensional model proposed by the *DSM-5* appears to reflect this combination of homogeneity in the core symptoms and heterogeneity in the severity levels, giving up on the idea that such heterogeneity can be best captured by a discreet number of mutually exclusive categories. Therefore, it is important that the "simplification" imposed in adopting a single diagnostic category should not limit the search for endophenotypes (i.e., subgroups). On the

contrary, it should stimulate more fine-grained investigations on individual differences within the spectrum, something that is sorely needed in the field.

Unfortunately, new changes to the diagnostic criteria will make the comparability of results across old and new studies difficult. For example, studies using samples diagnosed on the *DSM-IV* criteria (i.e., from 1994 to 2013) might include some individuals who would now fall into "Social Communication Disorder." However, information regarding the symptom severity (e.g., scores in diagnostic instruments such as the Autism Diagnostic Interview, Lord, Rutter, & Le Couteur, 1994; and the Autism Diagnostic Observation Schedule, Lord, Rutter, DiLavore, & Risi, 1999), language level, and cognitive abilities, typically provided in the most rigorous studies, will hopefully assist in making relevant comparisons across studies.

A major concern is that changes in the diagnostic definitions will affect our ability to monitor changes in the prevalence rates over time. The new classification, in excluding children who may have formerly received a diagnosis of PDD-NOS (and who may now be captured under Social Communication Disorder) may result in an "artificial" inversion of the increasing prevalence trend documented over the last decade (Fombonne, Quirk, & Hagen, 2011). However, as reasons for the increase in prevalence are still debated, the introduction of more stringent criteria may allow for a more rigorous test of prevalence changes.

The main reason of concern, from a research (and also clinical) point of view, however, lies in the possibility that the European classification system (i.e., the ICD-10); World Health Organization, 1992) will retain the current diagnostic definitions of PDD, thereby resulting in substantial differences in the way these conditions are conceptualised and defined in different parts of the world. In fact, one of the major achievements of the *DSM-IV* working group was to obtain convergence across the diagnostic criteria used in the two classification systems, thus creating shared clinical conceptualisation and terminology across countries. Having a cross-national definition has allowed comparison across studies conducted in different parts of the world, thus stimulating research (as reflected in the dramatic increase of autism research since the publication of the *DSM-IV* and ICD-10). It is unknown whether the World Health Organization will adopt the changes proposed for *DSM-5* in the next edition of the ICD (ICD-11). If not, the lack of international consistency will certainly be detrimental to research efforts undertaken to understand the nature, causes, and best-practice treatments for ASDs.

Cultural Implications

The decision to eliminate the distinction between autistic disorder and Asperger's disorder has begun to raise a cultural storm. Many people currently diagnosed with the latter condition do not see themselves as having autism, but rather identify themselves as a specific cultural minority (i.e., the "Aspie" culture; see websites such as aspieweb.net, wrongplanet.net, or aspie-world.net). This perspective, which has emerged in the last decade, considers Asperger's disorder as "a way of being" rather than a "disability," let alone a psychiatric condition. Similar to other cultural minorities, this "community" considers their

difference from the “mainstream” way of being as a value rather than a problem; a culture that should be supported and appreciated rather than treated. This position of “I don’t need treatment, just acceptance” implies a clear separation between persons with Asperger’s disorder and those with autism whose need for intervention is universally acknowledged. The lack of distinction between these conditions as proposed by the *DSM-5* criteria places proponents of the “Aspie culture” in a difficult position. However, it is important to separate the notions of “medical diagnosis” from those of “cultural” or “personal identity.” Systems of classification are created in order to communicate and share knowledge among clinicians and investigators, and to facilitate the implementation of legislations and guidelines to address the needs of individuals who have similar characteristics. Medical diagnoses are never intended to define a person and cannot capture the complexity of one’s personal and cultural identity, which includes a unique way of being in the world and relating to others, and a unique personal history. Therefore, we believe, and hope, that changes in medical/psychiatric classification systems will not affect the cultural appreciation of each individual’s unique way of being in the world, which is richer and more complex than any conceptualisation of diagnostic labelling, past, present, or future.

Conclusions

The bold changes proposed by the *DSM-5* committee regarding PDDs will undoubtedly impact upon the lives of people with ASD and their families in both direct and indirect ways. Overall, we believe that the impact will be a positive one. Importantly, the changes appear to be based on science rather than on lobbying and political negotiations. The relevance of the role of repetitive behaviours for differential diagnosis, the dimensional conceptualisation (as opposed to categorical approach), and the two-factor model of symptom clustering (as opposed to the symptom triad) all reflect advances in our understanding of ASD that have occurred in the past two decades (Kim & Lord, 2010; Lord & Jones, 2012; Mandy, Charman, & Skuse, 2012). The main reasons for concern include (a) the possibility that some individuals currently included within *DSM-IV* classification will now be classified under a new category (Social Communication Disorder) for which there are no treatment guidelines or legislation; (b) the possibility that the next edition of the ICD will not conform to the *DSM-5* criteria, thus jeopardising international consensus that has supported research advancement over previous decades; and (c) the possibility that the notion of multiple conditions within the spectrum is not clearly reflected in the new criteria. Of course, other changes might take place before the publication of the *DSM-5* (May 2013) with possible additional implications at different levels. It is likely that future advancements will lead to further changes in the way we conceptualise these complex disorders until, ultimately, diagnostic validation will be possible on a pathophysiological basis.

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