



Autism spectrum or autistic disorders: implications of DSM-5 for research and practice



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The year 2013 marks the 70th anniversary of Leo Kanner’s classic description autism [1]. Although cases had probably been noted before [2], it was Kanner’s genius to describe the combination of marked social disinterest (autism) and the over engagement with the nonsocial world (in dealing with change, insisting on sameness and engaging in repetitive routines). For the next several decades there was debate regarding the validity of autism. Some of this centered on the use of the word autism that suggested, perhaps, a continuity with schizophrenia. During the 1970s it became clear that autism was distinctive condition with strong genetic and neurobiological components. In 1978, Michael Rutter used Kanner’s original work and subsequent research to develop a more operational definition that emphasized social factors, communication problems, and unusual behaviors – all of the onset in the first years of life [3]. As a result of the increased body of work, autism was first officially recognized in the third edition of the DSM [4].

Before DSM-III previous editions were heavily theoretical and did little to enhance research and clinical work. DSM-III made extensive use of the research diagnostic criteria approach implemented in DSM-III by Spitzer [5]. Autism was included in a new overall class of disorders – the pervasive developmental disorders (PDD). Since that time, the definition of autism and disorders included in its category have been revised twice with the most recent version, DSM-IV, appearing in 1994 [6] with a text revision appearing a few years later.

For DSM-IV the definition for autism was based on a large international field trial involving almost 1000 cases seen by over 100 clinicians at more than 20 sites around the world [7]. This undertaking, supported by grants from the National Institute of Mental Health and the MacArthur Foundation, was done in coordination with the international analog of the DSM, the International Classification of Diseases (ICD). The diagnostic criteria for autistic disorder were refined, and Asperger’s disorder, a condition characterized by social

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vulnerabilities but with relatively preserved language, was added as were two rare conditions characterized by developmental deterioration. The 'subthreshold' category of PDD not otherwise specified was retained. A clear attempt was made in DSM-IV to have a system that worked well across the range of age and intellectual functioning observed in autism.

The coordination with ICD-10 meant that the same diagnostic system was used throughout the world. This was intended to facilitate research and appears to have been the case. The number of peer-reviewed papers on autism increased from approximately 350 in 1993 to over 2100 in 2011 – a sixfold increase. With more research, public awareness and interest grew dramatically and, with earlier detection and more effective treatments, outcomes for children with autism and related conditions have improved.

Overall the system has clearly worked well. The definition of Asperger's has been the most controversial and the one most in need of refinement (the text description was radically changed in DSM-IV-TR but no changes could then be made in the criteria). Even for this condition there has been a vast upsurge in research and it is probably fair to say that, given the complexities and recency of its inclusion, the issue of whether Asperger's merits its own diagnostic category remains unproven (to invoke the Scotch judicial concept) [8].

A fifth edition of the DSM is now in preparation. The proposed Autism Spectrum Disorder concept introduces several changes. Current subcategories will be collapsed into one broad, new category of autism spectrum disorder. In some ways the rationale for this is clear given that the term spectrum signifies a recognition of the broader range of the condition (itself recognized in some ways in DSM-IV) and the complex genetic correlates of this disorder(s) [9]. Some of the changes may have considerable practical implications. In DSM-IV the approach uses the traditional '3-basket' (social, communication-play and unusual behaviors) approach with a polythetic criteria set of 12 items (four in each 'basket') with a total of at least six criteria present (two of which must be social) for a diagnosis of autism. DSM-5 moves to a combination approach with one group of social-communication criteria (all of which must be met) and restricted interest criteria (where two of four must be present). The DSM-IV system for

autism gives the potential (at the minimum six criteria total level) of over 2000 combinations of criteria while the new DSM-5 approach means only a handful of combinations are possible. Even before independent data were available, several leading authorities noted the potential for substantive change and potential service implications [10,11].

From the side of data-based work the evolution of DSM-5 has presented challenges, for example, criteria can and are changed periodically. One of the first studies of the new criteria (but what is now a previous version of same) [12] noted some limitations relative to coverage, particularly in individuals with higher cognitive levels. In a study using the (more recent) criteria we re-analyzed the old DSM-IV data set and noted significant changes among more able individuals with well over 80% of the PDD not otherwise specified cases losing a diagnosis as did about 75% of the Asperger's cases, and a quarter of those with autism who were higher functioning) [13]. Several other papers reporting similar results have now been accepted for publication and others are currently undergoing editorial review and fairly consistently speak to the fact that despite the implicit suggestion of the name change, in fact, a more restricted definition results from DSM-5.

There are several important implications. Autism and related conditions are now generally thought to be among the most prevalent neurodevelopmental disorders; this may, by administrative fiat, no longer be the case. With the passage of federal legislation on educating children with disabilities, the diagnostic label has had critically important implications for eligibility for educational interventions. Such labels also guide in the selection of treatment approaches. At first blush the proposed introduction of one new diagnostic label is apparently not intended to address this problem, for example, the label 'Asperger's disorder' implies better verbal skills that may imply use of treatments not typically thought of as 'first line' in autism.

Other problems arise given the DSM 'dual use' approach, that is, unlike for ICD-10 where clinical descriptions and research criteria are provided in separate volumes. Major changes in diagnostic practice complicate interpretation of past and ongoing research. Generalization of results can be compromised. While there is little debate that, in some ways, the move to a single unitary concept has some advantages it also may

have some important limitations – particularly if the term ‘spectrum’ refers to a much narrower diagnostic concept.

Although the process for DSM-5 has differed in major ways from that used in DSM-IV the commitment to a solid research base for changes is important [10]. Unfortunately these issues arise at a moment when time is limited if the volume is to appear in 2013. One may argue that this pressure is unfortunate and not needed in an age where materials can be published online very quickly. Clearly discussion with both the clinical, research, and social-policy communities is needed. Hopefully the current debate will result in a stronger final product.

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