

Criteria, Categories, and Continua: Autism and Related Disorders in *DSM-5*

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Stories about autism spectrum disorders seem to be in the news almost daily. Whether the stories concern controversial research about vaccine risk, reports of new “cures,” or claims that the rate of autism is rising, everyone has read about autism. Despite intense research activity, diagnosis of autism remains behavioral, with biomarkers still elusive. With the forthcoming edition of the American Psychiatric Association’s *DSM-5*, to be published in 2013, the diagnosis of autism and related conditions continues to be the focus of a good deal of debate.

In this issue of the *Journal*, Mattila and colleagues¹ explore the prevalence of autism in a Finnish epidemiological sample by comparing current *DSM-IV* criteria with draft criteria for *DSM-5*. In a sample of almost 5,500 8-year-olds, approximately 4 per 1,000 met *DSM-IV* criteria for autism and 5 per 1,000 criteria for Asperger syndrome. The *DSM-5* draft criteria posted in February 2010 missed significant numbers of children with high-functioning autism or Asperger syndrome. The investigators suggest a number of improvements to those draft criteria, arguing for the importance of identifying these children so they will receive appropriate services. Updated draft criteria were posted by the Neurodevelopmental Disorders Workgroup at the end of 2010.² It is important to note that these proposed criteria, to be used in feasibility trials, differ from those used by Mattila and colleagues.¹ Nevertheless, their thoughtful and thorough article raises some concerns that are widespread in the autism community regarding what the *DSM-5* criteria may bring.³

Perhaps the biggest change from *DSM-IV* is the proposal to combine Asperger disorder, pervasive developmental disorder—not otherwise specified (PDD-NOS), and autistic disorder into a new category of *autism spectrum disorder* (ASD). Will this change decrease recognition and ser-

VICES for individuals previously receiving these diagnoses? Why lump together these different subgroups when the autism spectrum is known to be so wide, so heterogeneous? This editorial considers some of these issues from my perspective as a member of the *DSM-5* Neurodevelopmental Disorders Workgroup. I briefly review the aims behind our proposed changes to the diagnostic system: to reflect the widespread consensus that Asperger disorder is part of the autism spectrum, to clean up a currently hard-to-implement and contradictory diagnostic schema, and to do away with distinctions that are made idiosyncratically and unreliably across different clinicians.

First, we have proposed the term *autism spectrum disorder* because it reflects current widespread consensus that autism is best considered as existing on a spectrum with variable manifestations across life span, gender, and intellectual level and/or language ability. There is vast heterogeneity within this spectrum, with many attempts to carve up the spectrum into valid subgroups. A key question our workgroup has examined is whether there are meaningful differences between Asperger disorder and high-functioning autism. There has been no shortage of studies on this topic and some helpful recent reviews.⁴ Overall, it does not appear that those individuals on the autism spectrum who meet expected language milestones in the first 3 years (i.e., meet Asperger criteria) differ significantly from those who are delayed in early language, if one compares groups of equivalent current developmental level or IQ. Some studies have shown that the outcome of these two groups is very similar in adolescence and adulthood.⁵ There is no evidence of differential treatment response or etiology to date, and claims for a distinct neurocognitive profile in Asperger disorder have received mixed results. Taken together,

there is little evidence to support the current diagnostic distinction between Asperger disorder and high-functioning autism.

Second, the criteria for Asperger disorder in *DSM-IV* are flawed and hard to implement in practice, as highlighted by several researchers.⁶ At least two problems exist. It is often difficult to establish whether single words were spoken before 2 years of age and phrases by 3 years of age, as required for the Asperger diagnosis; individuals receiving this diagnosis typically come to clinics in middle childhood or later (not infrequently in adulthood), and parents' memory may be understandably vague. The other major problem with applying the current Asperger criteria comes from the precedence rule: diagnose Asperger disorder only if criteria for autistic disorder are not met. In fact, most people with Asperger disorder do meet criteria for autistic disorder because language and cognitive delay are not required, and most show "marked impairment in the ability to initiate or sustain a conversation" sufficient to meet the communication criteria for autism. A survey of more than 400 clinicians showed that almost half the young people receiving Asperger or PDD-NOS labels in fact met *DSM-IV* criteria for autistic disorder, with poor agreement between label given and criteria met.⁷

These problems with applying the *DSM-IV* Asperger disorder criteria result in wide variation in how the term *Asperger disorder/syndrome* is used in practice. A study by Lord and colleagues⁸ showed that the best predictor of which autism spectrum diagnosis a person received (Asperger disorder, PDD-NOS, or autistic disorder) was which clinic the individuals went to, rather than any characteristic of the individual. These different disorders are not reliably diagnosed or well distinguished in clinical practice; in contrast, the same studies suggest that clinicians show good agreement about who falls within versus outside the autism spectrum.

Our aim in proposing the new ASD diagnosis is to stop trying to "carve meatloaf at the joints" and instead recognize the essential shared features of the autism spectrum while attempting to individualize diagnosis through dimensional descriptors. Throughout *DSM-5* a new approach is being taken, complementing categorical diagnosis with a dimensional aspect. An individual with clinical-level needs, it is planned, will not only be assigned to a diagnostic category but also be described in terms of his/her individual levels of

symptom severity and general impairment. In the case of ASD, a young person might be dimensionally described as showing social and communication difficulties requiring very substantial support but restricted/repetitive behavior that requires much less support. In addition, the overall impairment measurements, which will cut across different diagnoses, should ensure that the individual's level of impairment from concomitant intellectual or language difficulties, mood disorder, motor or sleep problems, for example, are identified and well described. The important point is that, although the single general category of ASD may seem to blur important boundaries between groups such as Asperger disorder and autistic disorder, the intention in *DSM-5* is that individuals are described dimensionally, rather than being made to fit into narrow categories that they often do not really match. The latter is, perhaps, reflected in the fact that, of the *DSM-IV* diagnoses, PDD-NOS is far more commonly given than autistic disorder.⁹

Mattila and colleagues did not examine prevalence of PDD-NOS because of lack of clarity in the *DSM-IV* criteria. Indeed, PDD-NOS is a residual category, poorly defined and with little agreement across clinicians. Recently, Mandy et al.¹⁰ raised concerns that many children currently receiving this diagnosis will not meet proposed *DSM-5* criteria for ASD because of a lack of restricted/repetitive behavior. For these children, the proposed new neurodevelopmental diagnostic category of *social communication disorder* will be relevant.¹¹ This diagnosis, it is hoped, will more clearly and accurately capture the pattern of impaired social and communication abilities seen in the largest subgroup now labeled PDD-NOS.

A major concern for us in the workgroup is that no individual currently diagnosed with Asperger disorder or PDD-NOS who needs support will lose that support because of changes to the diagnostic system in *DSM-5*. It is our intention that all individuals with clinical levels of social-communicative impairment plus restricted/repetitive behavior will meet criteria for ASD, and that their individual levels of intellectual and language functioning will be noted and considered alongside this diagnosis. The data reported by Mattila and colleagues¹ in this issue provide important information for that process. They illustrate how important the text and examples will be in extending diagnosis to higher-functioning

individuals or those with complex patterns of compensation, despite clinical-level difficulties.

In conclusion, by folding Asperger disorder and PDD-NOS into ASD, we in the *DSM-5* workgroup hope to produce a clearer and simpler diagnostic system and improved recognition and diagnosis for those with autism spectrum disorders across all ages and ability levels. Asperger disorder in *DSM-IV* did a great service in raising awareness that some people on the autism spectrum have high IQ and good language. It is time to reintegrate Asperger disorder with the rest of the spectrum and to demand the same level of respect and lack of stigma for individuals across the full range of manifestations of ASD. *©*

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