

# Where next for autism?

Big changes are proposed to how autism and related disorders are diagnosed. It's troubling, says **Fred Volkmar**. Reform is needed, **Francesca Happé** replies

**Fred Volkmar**

AN EFFORT is under way to update the American Psychiatric Association's diagnostic guide – the *Diagnostic and Statistical Manual of Mental Disorders (DSM)*. In particular, changes suggested for diagnosis of autism are the focus of much debate.

There are clear reasons for changing and tweaking *DSM* categories and criteria in the light of new research, but the impact in this case is likely to be major. The current *DSM-IV* definition of autism was based on results from a large, grant-funded, collaborative study which I led in 1994 involving nearly 1000 cases (*American Journal of Psychiatry*, vol 151, p 1361).

It was meant to provide a balance of coverage over different ages and IQs, to be useful for both clinical work and research, and converged with the World Health

six yield an autism diagnosis. *DSM-5* proposes collapsing autism, Asperger's and PDD-NOS into a single "autism spectrum" category, combining and reducing criteria, vastly cutting the number of combinations that can lead to an autism diagnosis. This prompted me and my colleagues to reanalyse the *DSM-IV* field-trial data from 1994 for an upcoming edition of the *Journal of the American Academy of Child and Adolescent Psychiatry*. We found that many people, particularly the more cognitively able, would lose their diagnosis under the new regime.

We would not oversell our findings. Our study, like all, has its limitations. But two more groups have reported similar findings and other papers are in review.

What might this mean? It is possible that support for those in need will be hit, particularly in the US, where a diagnosis can trigger health insurance. Secondly, such a radical change would make it difficult to interpret the vast body of work done using *DSM-IV* – in 1993 there were about 390 peer-reviewed publications on autism. Last year over 2100 were produced.

Finally, the change of name to autism spectrum would suggest a broadened diagnostic concept when, if our reanalysis is correct, the opposite is the case. These are troubling issues. For such a major project, a more scientifically informed and engaged revision process is needed. ■

Fred Volkmar is director of the Child Study Center at Yale University School of Medicine and chief of child psychiatry at Yale New Haven Hospital

**Francesca Happé**

CHANGE causes anxiety. It is not surprising that draft changes to the *DSM*'s diagnostic criteria for autism and related conditions have aroused concern and publicity. So why change?

Diagnosis evolves, and the current criteria, while useful for recognising autism in middle childhood, have proved less so for those younger and older. *DSM-5* aims to encompass the full developmental range and improve recognition in neglected groups.

Anomalies in *DSM-IV* criteria for autism and other pervasive developmental disorders (PDDs), which includes the subgroups of

autistic disorder, Asperger's and PDD-NOS, have led to clinical inconsistency, leading to wide variations in how diagnoses of these are made. One study found it was the clinic attended that best predicted which label was given.

Most people diagnosed with Asperger's actually meet the *DSM-IV* criteria for autism. And research suggests there are no major differences between those with early language delay and those without – the feature differentiating autism and Asperger's in *DSM-IV*. The current split into three categories has little support in terms of genetic, neural, cognitive and other

differences. Clinicians show little agreement in telling the three apart but are good judges of what is on the autism spectrum.

That's why there is a proposal to fold these subgroups in with autism into a single category of autism spectrum disorder (ASD). The proposal is that the new diagnosis is complemented by a detailed description of an individual's profile of symptoms and associated difficulties.

There is concern that those with Asperger's or PDD-NOS might not meet ASD criteria. This is not the aim. With fellow members of the *DSM-5*'s neurodevelopmental disorders work group, I am working hard to ensure the full autism

**"I am working hard to ensure that the full autism spectrum is well recognised"**

spectrum is well recognised. We have proposed a new category of "social communication disorder" for those with some of the difficulties of autism but without rigid and repetitive behaviour – currently poorly described by the very diverse *DSM-IV* category of PDD-NOS. We are also seeking to aid recognition of ASD in adults coming for first diagnosis.

Our aim is to clean up a hard-to-implement and contradictory system. The proposals remain a draft to be reconsidered in the light of all relevant data. The current paper by Fred Volkmar's group reinterpreting a 1994 data set (see left) – which is not best suited to this purpose – will be taken into account, as will more directly relevant studies.

We hope the result will be a clearer and simpler diagnostic system, and better recognition and diagnosis for those with autism spectrum disorders across all ages and ability levels. ■

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