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**Research study led by Wales Autism Research Centre, Cardiff University**

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

**Frequently asked Questions and Answers**

Changes have been proposed to the international classification criteria for Autism, which has caused concerns that some people who currently have a diagnosis might not qualify for diagnosis according to the new criteria. Using a clinical interview method called the Diagnostic Interview for Social and Communication Disorders (DISCO) our international research team has demonstrated that using appropriate diagnostic rules, the DSM-5 criteria can be applied to correctly identify people who should receive a diagnosis of ASD across a range of age and ability. This study, therefore, may alleviate some concerns surrounding the publication of DSM-5. Here, we address some of the key questions about this research. If you would like to download the published article, you can click on this link: [http://onlinelibrary.wiley.com/doi/10.1111/jcpp.12085/abstract](http://onlinelibrary.wiley.com/doi/10.1111/jcpp.12085/abstract)

1. **What are DSM-IV-TR and ICD-10?**

DSM-IV-TR and ICD-10 are the current editions of International Classification Systems. These are descriptions of clinical conditions as well as guidelines for their diagnosis. The main classification system used throughout the world is the Diagnostic and Statistical Manual of Mental Disorders (DSM) and we are currently using the fourth version i.e. DSM-IV-TR. ICD-10 is the current version of the International Classification of Diseases, published by the World Health Organisation. ICD-10 is also widely used particularly in the UK and Europe, but also internationally, including in the United States of America.

There is a high degree of overlap in the descriptions of autism between DSM-IV-TR and ICD-10, they are almost identical, although the terms vary slightly. ICD-10 refers to Childhood Autism and DSM-IV-TR to Autistic Disorder. Both include certain subgroups including Asperger Syndrome. The current definition of both autism and Asperger Syndrome is based around a triad of impairments affecting 1) social interaction, 2) verbal and non-verbal communication, 3) and restricted and repetitive behaviours and interests.

2. **What is the difference between DSM-IV-TR and DSM-5?**

In May this year, the American Psychiatric Association (APA) published DSM-5. As part of the development process, drafts of the proposed
changes were made available for comment. Several research studies (including our own) have investigated these proposed changes. The new criteria have moved to using a single diagnosis of Autism Spectrum Disorder (ASD). This idea of an Autism Spectrum is a concept that was introduced by Lorna Wing and Judith Gould in the late 1970s. Furthermore, the guidelines have moved away from the triad of impairments and instead include just two domains. The social and communication domains in DSM-IV-TR and ICD-10 have been combined into a single domain with a second domain for repetitive and restricted behaviours. Although this first domain is referred to as the social communication domain, it looks as though the more repetitive aspects of language and communication such as repetitive questioning and use of stereotyped phrases are included within the second domain. According to the latest information, it appears that DSM-5 will have a somewhat more flexible approach to the age at which symptoms would need to be present for diagnosis.

Currently, the diagnostic criteria state that for a diagnosis of autism, symptoms must be present before 36 months. DSM-5 acknowledges that in some individuals, certain symptoms may not be evident until the demands of the social environment (e.g. school, college, work) placed on an individual exceed their level of functioning. The new criteria are also expected to include a rating of level of severity (Levels 1-3) of the behavioural symptoms (social communication and restricted repetitive behaviours) and how much these symptoms interfere with an individual’s everyday life.

Each of the two domains described by DSM-5 include different ‘groups’ of symptoms or sub-domains – these are shown in the picture 1.

Picture 1: The two domains in the DSM-5 (1. social-communication and 2. Repetitive and restricted patterns of behaviours) are shown in the circles. The sub-domains that make up the domains are shown in the squares.
The inclusion of a group of sensory sensitivities acknowledges the very high rate of these symptoms in individuals with ASD which have been noted across multiple sensory modalities including vision, hearing, smell and touch.

According to the latest draft of DSM-5, for an individual to meet criteria for an ASD they should have symptoms in all 3 of the social-communication sub-domains and any 2 (or more) of the 4 restricted and repetitive behaviour sub-domains (See picture 1 for sub-domains).

3. Will this affect diagnosis in the UK?

Although clinical teams in the UK can use DSM criteria, many use the ICD-10 criteria (developed by the World Health Organisation). These guidelines are likely also to be revised in the next couple of years. As with ICD-10 and DSM-IV-TR, we anticipate that the new version of ICD (ICD-11) will follow the approach adopted by DSM-5.

4. Will the changes to DSM-5 affect current diagnoses?

The DSM-5 committee have released a statement recommending that existing diagnoses should not be affected by the proposed changes, and that children and adults with existing diagnoses do not need to be re-diagnosed.

5. What are the concerns that have been raised about DSM-5?

The main concern about DSM-5 is that the new criteria might miss some people who currently qualify for a diagnosis, especially high ability individuals and those who would currently receive a diagnosis of Asperger Syndrome.

6. Does the new study support these concerns?

No, the results from our study indicated that DSM-5 does not significantly under-diagnose people who would currently receive a diagnosis of Autism or Asperger Syndrome. This was true for children, adolescents and adults with both high and low ability.

7. Who did this study?

The international research team was led by researchers from the Wales Autism Research Centre (WARC, based at Cardiff University) and included collaborators from Universities in Newcastle, Belgium, the Netherlands and the UK National Autistic Society. Some of the authors on the paper are shown in Picture 2 (left to right: Sarah Carrington, Judith Gould, Sue Leekam, and Rachel Kent).

8. How was the study done?

This study used information from a parent clinical interview (the Diagnostic Interview for Social and Communication Disorders – the DISCO) to investigate the DSM-5 criteria. Items from the DISCO were selected to address each of the behaviours included in the DSM-5 description of ASD. The DISCO covers a broad range of behaviours, symptoms and aspects of development necessary for the differential diagnosis of autism and related disorders. This meant that the researchers were able to...
consider all of the behaviours described in the DSM-5 criteria. In the social-communication domain there are three different types of behaviours described and it is necessary to have at least one example of each type of behaviour. In the repetitive and restricted behaviour domain there are four different types of behaviours described and individuals need an example of at least two of these four types of behaviours. Using a variety of statistical techniques the team were able to set the number of examples of behaviour that were included and compare how well each of these symptom combinations were able to correctly identify people with a diagnosis of Autism or Asperger Syndrome compared with people with a language disorder or intellectual disability.

9. Why does this study show different results to previous research?

This study is the first to use the Diagnostic Interview for Social and Communication Disorders (DISCO) to evaluate the new DSM-5 criteria. Other studies have used symptom checklists of diagnostic tools that were developed to fit with the DSM-IV-TR criteria. The DISCO is different because it was designed to include a broader range of symptoms and behaviours as part of a comprehensive clinical assessment for individuals with a possible autism spectrum disorder rather than the published international diagnostic guidelines. Although it is possible to use the DISCO to make a diagnosis according to the existing diagnostic guidelines, it also includes additional information that helps clinicians to fully understand each person’s individual profile. This feature of the DISCO allowed us to capture all of the behaviours described by DSM-5 in more detail than previous studies, which may have allowed us to better represent the DSM-5 criteria.

DSM-5 describes the set of behaviours that should be present for a diagnosis of ASD. This study was the first to investigate how varying the number of examples of these behaviours impacts on who receives a diagnosis. The study, therefore, indicates that this is an important consideration when developing new tools for diagnosis.

10. If DSM-5 does not affect who gets a diagnosis, why has it been changed?

Although the results from our study agree with the DSM-5 committee that the changing criteria will not affect who will receive a diagnosis, it is important that diagnostic criteria are updated to reflect the research evidence. The research findings indicate the need for a more inclusive ‘spectrum’ description and have supported the move from a triad of impairments to the two social-communication and restricted, repetitive behaviour domains described by DSM-5. In addition, the inclusion of sensory atypicalities reflects the high prevalence of these features reported in research studies over the past few years including parent report and personal accounts of individuals with ASD.

11. What are the next steps?

More research will be needed to examine how well the DSM-5 criteria are working as clinicians begin to use these guidelines when making diagnoses for individuals across the lifespan- from early preschool to adults who may be seeking a diagnosis much later in life. Other research questions include whether the new criteria work for females with autism/ASD. Our study did include some girls and women with ASD but as with most research to date, the number of females in the study did not allow us to look in any detail at individuals of different ages or abilities.
12. What is the DISCO?

**Clinical use:** The Diagnostic Interview for Social and Communication Disorders or DISCO is a semi-structured diagnostic interview that is used with parents or caregivers of an individual. The DISCO interview was designed by Lorna Wing and Judith Gould and their concept of an autism spectrum. Its content is based on behaviours present in individuals seen in clinical practice and this means there are a broad range of items. Importantly, the DISCO was not based around the concepts set out by the international classification systems like earlier versions of the DSM but with a view of autism as a spectrum. Further information about the DISCO can be found on the National Autistic Society’s website ([http://www.autism.org.uk/our-services/diagnosing-complex-needs/the-diagnostic-interview-for-social-and-communication-disorders-disco.aspx](http://www.autism.org.uk/our-services/diagnosing-complex-needs/the-diagnostic-interview-for-social-and-communication-disorders-disco.aspx)).

**Research use:** Although the DISCO was originally developed for clinical practice, it has been extensively researched by research teams in the UK, Sweden, the Netherlands, Belgium and Japan. Several research studies have established its validity and reliability in comparison with other diagnostic tools such as the Autism Diagnostic Interview-Revised (ADI-R) and the Autism Diagnostic Observation Schedule (ADOS). Another set of research studies has used the DISCO to study patterns of core and non-core autistic traits in children both with and without ASD. A list of publications is shown at the end of this document.

In addition to our DSM-5 paper our international team is carrying out other research on the DISCO.

13. Who are the research team?

The research team was led by researchers in the Wales Autism Research Centre, which is directed by Prof. Susan Leekam. The joint first authors on this study are Rachel Kent and Dr Sarah Carrington. You can find out more about work focusing on diagnosis within the Wales Autism Research Centre by clicking on this link: [http://sites.cardiff.ac.uk/warc/research/research-diagnosis/](http://sites.cardiff.ac.uk/warc/research/research-diagnosis/). You can find out more about the research team by clicking on their picture below.

- Rachel Kent, WARC
- Dr Sarah Carrington, WARC
- Prof Ann Le Couteur, Newcastle University
- Dr Judith Gould, National Autistic Society
- Dr Lorna Wing, National Autistic Society
- Dr Jarymke Maljaars, University of Leuven/Leiden University
- Prof Ilse Noens, University of Leuven
- Prof Ina van Berckelaer-Onnes, Leiden University
- Prof Susan Leekam, WARC
14. Contact details

If you have any questions about the study, you can get in touch with us by email at warc@cardiff.ac.uk or you can email us individually at kentrg@cardiff.ac.uk (Rachel Kent), carringtonsj@cardiff.ac.uk (Sarah Carrington) or leekamsr@cardiff.ac.uk (Susan Leekam). Our postal address is Wales Autism Research Centre, School of Psychology, Cardiff University, Tower Building, Park Place, Cardiff, CF10 3AT.

15. What do the changes mean for the research community?

In a recent video message, Prof. Susan Swedo (Chair of the DSM-5 Neurodevelopmental Disorders Work Group) indicated that the changes to DSM-5 will have little, if any, impact on research. The majority of research studies over the past few years have adopted the term ASD. Moreover, given that who will receive an appropriate ASD diagnosis is unlikely to change, the way in which individuals are invited to take part in research should not be affected. You can watch the video message from Prof. Swedo at the following link: http://www.psychiatry.org/practice/dsm/dsm5/dsm-5-video-series-impact-of-changes-to-autism-spectrum-disorder

There has been some criticism of the reliance of international diagnostic guidelines on descriptions of symptoms, rather than on biological ‘markers’ of conditions, including genetics or brain imaging information. For example, the National Institute of Mental Health in America has taken a strong position regarding the continued use of diagnostic ‘categories’ in DSM-5 (you can read more at http://www.nimh.nih.gov/about/director/2013/transforming-diagnosis.shtml). There has been growing recognition in the research community of a high degree of overlap between conditions such as ASD, ADHD, and other neurodevelopmental disorders, both in terms of behaviour and genetic/neurobiological features. Research is on-going to understand more about this overlap and potential biological markers, and the descriptions of symptoms provided by guidelines such as ICD-10 and DSM-5 are an important framework in which to develop this work.

DISCO references


