

The Research Domain Criteria (RDoC) – a new dawn for neurodiversity research?

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It is 75 years since Donald Triplett became the first person to be diagnosed with autism. Since then, ‘autism spectrum disorder’ (hereafter ‘autism’) has come to be considered a common condition, with an estimated prevalence above one per cent (Centres for Disease Control, 2014), and an ever-growing prominence in the public consciousness. Nevertheless, its value as a diagnosis continues to be contested (e.g., Gillberg, 2010; Foss-Feig et al, 2016). In this editorial, I outline some critiques of autism as a diagnostic category, and point towards a recent development in mental health science as a potential remedy for these.

By convention, a psychiatric diagnosis is judged according to three criteria. First, it should be *reliable*, meaning that it can be applied consistently by different diagnosticians in different settings (e.g., Spitzer, 1978). Second, it should have *clinical utility*, such that it communicates useful information about the characteristics, needs and future prospects of a diagnosed person (Jablensky, 2016). The third criterion, that of *validity*, is epistemologically contentious and harder to define. In its broadest sense, the validity of a concept concerns how well it corresponds to external reality (Jablensky, 2016). In terms of nosological validity this has been taken to mean that a diagnosis should describe a discrete set of characteristics that cluster together because they arise from a shared underlying neurobiological atypicality (Kendell & Jablensky, 2003).

How does the diagnosis of autism measure up against these criteria? Autism spectrum disorder, when diagnosed by trained clinicians using standardised measures, is reliable (Lord et al., 2011). Furthermore, there is evidence that the concept of autism can have clinical utility, at least in settings where resources are available to autistic people. This is because an autism diagnosis can provide a shorthand description of a person's strengths and difficulties, and point towards potentially beneficial clinical, educational and social support (Ruiz-Calzada et al., 2012). Further, many autistic people, especially those diagnosed as adults, experience their diagnosis as a 'not guilty verdict' – a way of narrativising their lives in a kinder, less blaming way than would occur in the absence of a diagnosis (e.g., Punshon et al., 2009).

Despite its reliability and utility, there continue to be doubts raised about the value of autism as a diagnosis. These centre on the question of its validity. The first major problem is that the diagnosis is very heterogeneous, encompassing a wide range of individuals whose autistic symptoms arise from multiple different underlying causes. There is not a single autism, but rather there are hundreds, or even thousands, of 'autisms' (Jeste & Gershwind, 2014). This means that researchers seeking to understand autism are faced with an impossible task. They assemble a sample of people who meet official (DSM-5) criteria for autism spectrum disorder; and within this sample are diverse individuals whose conditions have various underlying mechanisms, who have diverse needs, and who will benefit from different interventions. Researchers have long been aware of how this problem has hampered the progress of autism genetics, and it

certainly impacts upon most other areas of autism research too (Abrahams & Geschwind, 2008).

A second problem with the current diagnostic conceptualisation is that it treats autism as a discrete condition, where as in reality it is part of a wider spectrum of neurodevelopmental atypicality. This is shown by the fact that characteristic autistic symptoms almost never occur in isolation, but comprise part of a constellation of co-existing features, including behaviours that get labelled as attention deficit/hyperactivity disorder (ADHD), developmental coordination disorder (DCD), oppositional defiant disorder, anxiety conditions, and tic disorders, among others (e.g., Gillberg et al., 2010). To describe an independent, circumscribed condition such as autism, as representing a category which is distinct from ADHD, DCD and other conditions, is to fail to describe the nature of human neurodevelopment as it really is.

These limitations to the scientific validity of the autism diagnosis matter. They constrain our ability to find the mechanisms that underlie autistic characteristics and experience, and therefore impede the development of effective interventions to support autistic people and their families.

This validity problem is not limited to autism: in fact, it applies to almost all the diagnoses in DSM-5. Recently, the National Institute of Mental Health (NIMH), which is the world's largest funder of mental health research, attempted to address the situation, by introducing an alternative way of classifying mental health conditions, which they call Research Domain Criteria (RDoC). The idea

was to introduce a parallel classification system to DSM-5, which describes validated dimensions of functioning relevant to mental health that can be linked to underlying biological systems (Insel et al., 2010). The aim is to give researchers a descriptive framework that more closely reflects the true nature of how the brain gives rise to experience and to behaviour.

Some have heralded the RDoC as providing a new dawn for the study of psychopathology (e.g., Cuthbert, 2014). What is their relevance to autism? RDoC have not yet been widely adopted in autism research. It is now 10 years since they were first vaunted, yet a PubMed search of the terms 'RDoC' and 'autism', (conducted in May 2018) returned only 18 papers, of which 5 contained original data. My view is that in their current form, the RDoC are of only limited use to autism researchers. Whilst they map autism-relevant social and communication difficulties, their relevance to other central elements of autism is less clear. For example, the current RDoC framework contains very little concerning the atypical sensory processing that is so central to autistic experience.

Nevertheless, the RDoCs do have potential value to autism research. First, the RDoCs are not intended to replace DSM-5, but rather are designed to provide a parallel, more scientifically-productive way of conceptualising and studying the sorts of conditions described in DSM-5. The advantage of this is that adopting RDoC's does not mean having to abandon the clinically useful construct of autism, which is central to the lives and identities of millions. Second, the architects of the RDoCs were clear that their current framework is not comprehensive, and indeed is designed to be extended and embellished. So there

is nothing to stop autism researchers from adding their own RDoC candidates, and investigating these. Third, the RDoCs are intended as a trans-diagnostic framework, and so can account for the fact that autism is part of a wider spectrum of neurodevelopmental atypicality. It will be productive to investigate RDoC dimensions that cross our current diagnostic boundaries, for example in samples that include individuals with ADHD and autism, as well as those with sub-clinical traits of these conditions. Such a trans-diagnostic and dimensional RDoC approach has already been adopted in other areas, for example in a study that investigated the neural basis of reward processing in schizophrenia and depression (Arrondo et al., 2015).

Finally, I argue that RDoCs can help resolve a fundamental disagreement that is at the heart of contemporary autism culture, on the question of whether it is ever acceptable to look for a 'cure' for autism. Until recently, many autism researchers assumed it was their job was to seek a cure for autism. The prevention and cure of autism continues to be, for some, a legitimate goal of autism research. Yet this idea is offensive to many autistic people, who see such a stance as the sinister imposition of normative values on a disempowered, atypical minority, akin to historical efforts to 'cure' gay people of their homosexuality using psychotherapy. The RDoC provide a way to navigate this treacherous terrain. This is because they do not seek to treat autism at a single entity, but rather understand the experiences of autistic people as arising from the action of multiple systems. Therefore an RDoC approach would allow us to attempt to address some aspects of autism, but not others (Foss-Feig et al., 2016). Within this framework, researchers could focus efforts on developing interventions for

elements of autistic experience that are widely agreed to be aversive, such as sleep problems and high rates of anxiety, without an overall goal of 'curing' autism. Crucially, decisions about what aspects of autistic experience to focus on should be decided based on debates that prioritise the views of autistic people, as well as parents, scientists and clinicians.

In this way, RDoC can provide a framework for understanding atypical neurodevelopment in a way that combines scientific rigour and genuine respect for the experiences and views of autistic people. Such an endeavour could hasten progress towards there being an evidence base for helping neurodiverse people live more satisfying lives.

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REFERENCES

- Abrahams, B. S., & Geschwind, D. H. (2008). Advances in autism genetics: on the threshold of a new neurobiology. *Nature reviews genetics*, 9(5), 341.
- Arrondo, G., Segarra, N., Metastasio, A., Ziauddeen, H., Spencer, J., Reinders, N. R., ... & Murray, G. K. (2015). Reduction in ventral striatal activity when anticipating a reward in depression and schizophrenia: a replicated cross-diagnostic finding. *Frontiers in psychology*, 6, 1280.
- Centers for Disease Control and Prevention. (2014). Autism spectrum disorders: Data and statistics. Retrieved November, 26, 2014.
- Cuthbert, B. N. (2014). The RDoC framework: facilitating transition from ICD/DSM to dimensional approaches that integrate neuroscience and psychopathology. *World Psychiatry*, 13(1), 28-35.
- Foss-Feig, J. H., McPartland, J. C., Anticevic, A., & Wolf, J. (2016). Reconceptualizing ASD within a dimensional framework: Positive, negative, and cognitive feature clusters. *Journal of autism and developmental disorders*, 46(1), 342-351.
- Gillberg, C. (2010). The ESSENCE in child psychiatry: early symptomatic syndromes eliciting neurodevelopmental clinical examinations. *Research in developmental disabilities*, 31(6), 1543-1551.

- Insel, T., Cuthbert, B., Garvey, M., Heinssen, R., Pine, D. S., Quinn, K., ... & Wang, P. (2010). Research domain criteria (RDoC): toward a new classification framework for research on mental disorders.
- Jablensky, A. (2016). Psychiatric classifications: validity and utility. *World Psychiatry, 15*(1), 26-31.
- Jeste, S. S., & Geschwind, D. H. (2014). Disentangling the heterogeneity of autism spectrum disorder through genetic findings. *Nature Reviews Neurology, 10*(2), 74.
- Kendell, R., & Jablensky, A. (2003). Distinguishing between the validity and utility of psychiatric diagnoses. *American journal of psychiatry, 160*(1), 4-12.
- Lord, C., Petkova, E., Hus, V., Gan, W., Lu, F., Martin, D. M., ... & Algermissen, M. (2012). A multisite study of the clinical diagnosis of different autism spectrum disorders. *Archives of general psychiatry, 69*(3), 306-313.
- Ruiz Calzada, L., Pistrang, N., & Mandy, W. P. (2012). High-functioning autism and Asperger's disorder: Utility and meaning for families. *Journal of Autism and Developmental Disorders, 42*(2), 230-243.
- Punshon, C., Skirrow, P., & Murphy, G. (2009). 'Thenot guilty verdict' Psychological reactions to a diagnosis of Asperger syndrome in adulthood. *Autism, 13*(3), 265-283.

Spitzer, R. L., Endicott, J., & Robins, E. (1978). Research diagnostic criteria: rationale and reliability. *Archives of general psychiatry*, 35(6), 773-782.