

This is an Open Access document downloaded from ORCA, Cardiff University's institutional repository:<https://orca.cardiff.ac.uk/id/eprint/143266/>

This is the author's version of a work that was submitted to / accepted for publication.

Citation for final published version:

Sonuga-Barke, Edmund and Thapar, Anita 2021. The neurodiversity concept: is it helpful for clinicians and scientists? *The Lancet Psychiatry* 8 (7) 10.1016/S2215-0366(21)00167-X

Publishers page: [http://dx.doi.org/10.1016/S2215-0366\(21\)00167-X](http://dx.doi.org/10.1016/S2215-0366(21)00167-X)

Please note:

Changes made as a result of publishing processes such as copy-editing, formatting and page numbers may not be reflected in this version. For the definitive version of this publication, please refer to the published source. You are advised to consult the publisher's version if you wish to cite this paper.

This version is being made available in accordance with publisher policies. See <http://orca.cf.ac.uk/policies.html> for usage policies. Copyright and moral rights for publications made available in ORCA are retained by the copyright holders.



## **The neurodiversity concept: Is it helpful for clinicians and scientists?**

Attention-deficit/hyperactivity disorder (ADHD) and autism spectrum disorder (ASD) are currently conceptualised as discrete, categorical neurodevelopmental disorders (NDs) that originate in early development<sup>1</sup> and involve brain dysfunction<sup>2</sup>. From one perspective, current definitions provide important clarity for clinical practice and ensure we are guided by research progress over the last 40 years<sup>3</sup>. In contrast, others have argued that alternative ways of thinking are needed. Some challenges to current concepts are empirical. For instance, research shows that neither ADHD or ASD are, in fact, categorical in nature but rather behave as population dimensions with no clear-cut boundary into disorder<sup>1</sup>. The different neurodevelopmental disorders also show very marked phenotypic and genetic overlap<sup>1,4</sup>. Furthermore, neurodevelopmental conditions are highly heterogeneous - individuals with similar clinical presentations display very different neuro-cognitive profiles<sup>5,6</sup>. Finally, for ADHD and possibly ASD, emerging evidence of adult-onset forms could be viewed as challenging their neurodevelopmental status<sup>7,8</sup>. Alongside, but largely independent of empirical challenges<sup>9,10</sup>, has come an ideologically-inspired proposal to completely rethink the way we understand these conditions – replacing the notion of disorder underpinned by dysfunction with that of neurodiversity.

Neurodiversity is a concept that shares much in common with civil rights thinking. The term has been adopted by many of those who are affected although there is much variability in how radically it is interpreted. Some have questioned/rejected the notion that ADHD and ASD is caused by brain dysfunction and so intrinsically impairing. From the neurodiversity perspective these conditions are seen as variations in brain structure and function that lead to ways of thinking and behaving that are different from most people in a society – differences that, crucially, can be advantageous (both to the individual and the group) under some circumstances and disadvantageous under others. The

impairment suffered by people with neurodiversity occurs, not as an intrinsic part of a disorder, but because there is a mismatch between their ways of thinking and behaving and their environments - environments structured in accordance with neurotypical perspectives. Furthermore, neurotypical perspectives can undervalue and undermine the unique gifts, strengths and qualities that neurodiverse individuals bring to a situation. This can lead to shame/stigma and low self-worth which can lead to mental health problems. The neurodiversity movement privileges the perspectives and experiences of neurodiverse individuals over clinicians and scientists and encourages them to take control of narratives about their lives.

Adopting a neurodiversity perspective on ADHD and ASD will change the focus and purpose of research and how it is practised. While disorder-based and neurodiversity-inspired researchers can be seen as having the same ultimate goal – to provide an evidence-base to reduce the impairment and suffering experienced by neurodiverse people - they go about achieving this in radically different ways. Research carried out within the disorder-based framework, with which we are most familiar, focuses on understanding the bio-psycho-social basis of dysfunction within the individual so that this can be targeted, symptoms can be alleviated, and associated impairment can therefore be reduced. By adopting a neurodiversity framework, the researcher will turn the spotlight on: i) the neurodiverse person's physical and social environment in an attempt to understand how its structure constrains and limits them and leads to impairment and to undermining their sense of self and wellbeing and; ii) the experience of living with ADHD and ASD within those environments. There will also be a focus on uncovering the strengths and talents of neurodiverse people – either those that may be linked closely to their condition (e.g., creativity and energy in ADHD; an eye for detail and orderly thinking in ASD) or obscured by it under normal circumstances. Finally, there will be a strong interest in understanding the attitudes of neurotypical individuals and organisations towards neurodiverse people and how these create risks for stigma, low self-esteem and mental health problems. The neurodiversity perspective will also lead to a new more participatory way of doing

research with neurodiverse individuals collaborating in the co-design of studies and co-creation and interpretation of knowledge – forging a shared narrative of what it means to have ADHD or ASD and ways that impairment can be alleviated by transforming social structures. From a radical neurodiversity perspective, the goal of understanding the pathophysiology of ADHD and ASD could be relegated to being of secondary importance – perhaps as a way of studying individual-environment match and mismatch.

The research priorities encouraged by a neurodiversity orientation are mirrored at the level of clinical practice. The focus again is shifted to the environment – with a strong focus on adapting environments in school, the workplace and other settings to make them neurodiverse friendly and on changing attitudes of neurotypical people. This would include setting a societal agenda that focuses on adjusting environments to better suit those who are different. This contrasts with the expectation of the specialist clinician “fixing” or removing the deficit. The paradigm could emphasise more societal and public health responsibilities for supporting neurodiversity. This would include dealing with stigma, stereotypes and discrimination via public education, training, policy and legislation. An advantage of these approaches is that they reduce complete dependence on specialist health care provision where a diagnosis is often required for allocating resources including changes to school or the workplace. Interventions can also look to transform the way that neurodiverse people see themselves focusing on a strengths-based perspective that facilitates strengths and talents.

We eschew a radical interpretation of neurodiversity because a diagnosis and treatment has been shown to be helpful for many. However, rather than a complete reliance on disorder-based concepts and related treatment approaches, we can see many advantages of incorporating the concept of neurodiversity alongside mainstream research and clinical practice. Indeed, there is no contradiction between traditional approaches that look to give neurodiverse individuals additional resources

through clinical treatment and neurodiverse approaches that look to adapt environments and transform neurotypical attitudes – both approaches are beneficial and together will improve the lives of neurodiverse people.

Authors: Edmund Sonuga-Barke<sup>1</sup> and Anita Thapar<sup>2</sup>

<sup>1</sup> School of Psychiatry, Institute of Psychiatry, Psychology & Neuroscience, King's College London.

<sup>2</sup> Child and Adolescent Psychiatry Section, Division of Psychological Medicine and Clinical Neurosciences and MRC Centre for Neuropsychiatric Genetics and Genomics, Cardiff University School of Medicine, Cardiff

Address for correspondence: thapar@cf.ac.uk

**Disclosures:**

Anita Thapar is on the board of ADHD Foundation: A UK neurodiversity charity. Her research on neurodevelopmental disorders is funded by the Wellcome Trust and Waterloo Foundation. Edmund Sonuga-Barke has received consultancy from Neurotech Solutions, grant funding from QB-Tech and speaker fees from Takeda and Medice. He is the editor-in-chief of the Journal of Child Psychology & Psychiatry from whom he receives an honorarium. His research is supported by the Maudsley NIHR BRC, the ESRC, MRC and NIHR.

## References

1. Thapar A, Cooper M, Rutter M. Neurodevelopmental disorders. *Lancet Psychiatry*. 2017 Apr;4(4):339-346.
2. Posner J, Polanczyk GV, Sonuga-Barke E (2020). Attention-deficit/hyperactivity disorder. *Lancet*, 395 (10222), 450-462.
3. Sonuga-Barke E (2020). "People get ready": Is mental disorder diagnostics ripe for Kuhnian Revolution. *J Child Psychol Psychiat*, 61, 1-3.
4. Kushki, A., Anagnostou, E., Hammill, C. *et al.* Examining overlap and homogeneity in ASD, ADHD, and OCD: a data-driven, diagnosis-agnostic approach. *Transl Psychiatry*, 9, 318 (2019).
5. Stevens MC, Pearlson GD, Calhoun VD, Bessette KL (2018). Functional Neuroimaging Evidence for Distinct Neurobiological Pathways in Attention-Deficit/Hyperactivity Disorder. *Biol Psychiat: Cog Neurosci Neuroimaging*, 3, 675-685.
6. Geurts H, Sinzig J, Booth R, Happe F (2014) Neuropsychological heterogeneity in executive functioning in autism spectrum disorders, *International J Dev Disabil*, 60, 155-162
7. Asherson P, Agnew-Blais J. (2019). Annual Research Review: Does late-onset attention-deficit/hyperactivity disorder exist? *J Child Psychol Psychiat*, 60, 333-352.
8. Riglin, L, Wootton, R, Livingston L et al. (2021) Variable emergence of Autism Spectrum Disorder symptoms from childhood to early adulthood. *American Journal of Psychiatry*. *In press*.
9. Mandy W. (2018). The Research Domain Criteria: A new dawn for neurodiversity research? *Autism*, 20, 642-644.
10. Musser ED, Raiker JS (2019). Attention-deficit/hyperactivity disorder: An integrated developmental psychopathology and Research Domain Criteria (RDoC) approach. *Comprehensive Psychiat*, 90, 65-72.