



# Conceptual issues in neurodevelopmental disorders: lives out of synch

Jennifer Clegg<sup>a,b</sup>, Alinda Gillott<sup>b</sup>, and Jo Jones<sup>b</sup>

## Purpose of review

Current revision of the two major psychiatric classification systems has elicited particular comment on neurodevelopmental disorders, which have seen increased provision of specialist clinical services, user group activity, fictional and biographical accounts, and research. Philosophical scrutiny of autism research and literature provides an additional perspective.

## Recent findings

Neurodevelopmental disorders show considerable overlap neuropsychologically, physiologically and genetically. They overlap diagnostically with schizophrenia, personality disorders, anxiety and depression. Of the two main diagnostic groups, there is more evidence of change with maturation in autism spectrum disorder than attention-deficit hyperactivity disorder. Interventions should combine cognitive, affective and embodied aspects of these disorders, and encompass the individual and their social environment. There is considerable evidence of the toll that caring for people with neurodevelopmental disorders exerts on parents.

## Summary

Neurodevelopmental disorders are multifaceted: research addressed to connection rather than further Balkanization is more likely to be fruitful. Clinicians should consider which facets are displayed symptomatically to enable people to grow through rather than surrender to their impairments. Social scaffolding optimizes functional well being. Future research should take into account the tensions in the relationship between research and user groups, and examine the experiences of adults and of the spouses and partners of those affected.

## Keywords

affective, cognitive, conceptual, embodied, neurodevelopmental disorders

## INTRODUCTION

ICD-10 describes a distinct axis of neurodevelopmental disorders as a group of conditions with three main criteria: onset in infancy or childhood; impairments related to central nervous system maturation; and expressed steadily without remissions or relapses. DSM-IV does not put neurodevelopmental disorders onto a separate axis, but uses broadly similar descriptors. Although these disorders tend to lessen with age, deficits largely continue into adult life and are more common in men than women. A recent systematic review indicated that the diagnosis is not completely stable: 85–89% remained in the category longitudinally [1]. The authors suggest that movement into and out of autism spectrum disorder (ASD) over time may have resulted from different interpretations of DSM-IV criteria but also from its over-inclusivity. Both classification systems are undergoing revision, with

DSM-5 expected in 2013 and ICD-11 in 2015. Autism and attention-deficit hyperactivity disorder (ADHD) are the most frequently occurring neurodevelopmental conditions [2]. In 2008, cerebral palsy, epilepsy, intellectual disability, brain injury and single-gene conditions with cognitive deficits were ruled out by some experts [3] on the grounds that neurodevelopmental disorders have multiple causes. Nevertheless, all these except the single-gene conditions are included in the current definition on

<sup>a</sup>University of Nottingham and <sup>b</sup>Nottinghamshire Healthcare NHS Trust, Nottingham, UK

Correspondence to Jennifer Clegg, Institute of Mental Health, University of Nottingham, Innovation Park, Triumph Road, Nottingham, NG7 2TU, UK. Tel: +44 115 8542206; fax: +44 115 8542204; e-mail: Jennifer.Clegg@Nottingham.ac.uk

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Voluntary groups have been very significant in drawing attention to difficulties, gathering data and funding research. Yet, although medical researchers are alert to the implications of working with drug companies which inevitably have their own agenda, there is no equivalent reflection about research with interest groups that, by definition, campaign for the continued existence of their condition. We question the appropriateness of academic articles that conclude by directing readers to an association representing a particular condition and listing its postal address, phone number and e-mail [34]. There is a recognition that the perspective taken by research teams is already affected by their starting point [12<sup>■</sup>] in, for example, ASD or ADHD or personality disorders; and multicentre trials for neurodevelopmental conditions note differences in diagnosis made by different research centres with regard to both ASD [35<sup>■</sup>] and ADHD [36<sup>■</sup>]. The involvement of interest groups contributes to social justice and may do something to address the complex matter of perceived research relevance, but it may also introduce sources of bias and increase fragmentation at the expense of conceptual coherence.

## CONCLUSION

Losing the term 'pervasive' may erode our ability to conceptualize the broad impact that neurodevelopmental conditions have upon lives. These lives are 'out of synch' with other people and sometimes 'out of synch' within themselves. This is mirrored by difficulty synchronizing meanings and understandings of these multifaceted conditions across the research groups. The evidence is detailed but fragmented: we regard DSM-5 reduction of the number of available diagnoses and facilitation of overlapping diagnoses to be a useful direction of travel. We welcome their use of website interactivity to engage interest groups in dialogue, but consider that the relationship between research, clinical services and interest groups requires further reflection.

Striving to understand which 'facets' of neurodevelopmental conditions are displayed symptomatically may be a helpful conceptualization that can take clinicians forward with each individual and their social context. Good formulations are likely to incorporate aspects of what we have termed the miswiring, dysregulation and sociality hypotheses, and take into account the social environments co-created with parents, partners and staff. When support from others is effective, the impairments resulting from neurodevelopmental disorders become hidden as individuals appear more 'in synch' than they really are: when some life-event destabilizes the person or their support, the extent of their

condition emerges. More research about the role of important others is needed to identify the ways that they enable people with neurodevelopmental disorders to experience a satisfactory quality of life. When this works well, it allows them to grow through rather than surrender to their impairments.

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## Conflicts of interest

*Dr Clegg has no conflicts of interest to declare. Drs Jones and Gillott are both employed by the Nottinghamshire Healthcare NHS Trust providing a specialist service to adults with Asperger's syndrome. Dr Gillott has also received payment for preparation of court reports concerning adults with Asperger's syndrome.*

## REFERENCES AND RECOMMENDED READING

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- of special interest
- of outstanding interest

Additional references related to this topic can also be found in the Current World Literature section in this issue (pp. 299–300).

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