Conceptual issues in neurodevelopmental disorders: lives out of synch

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**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
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\*] 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\*] and ADHD [36\*]. 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

Papers of particular interest, published within the annual period of review, have been highlighted as:

- 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).


5. This study reviews the ‘autism fiction’ to examine how it is framing the way that people with ASD, families and members of the public understand autism. Harmful when it elaborates autistic children having secret powers, and parents who search hard enough can find the key to unlock them.


7. Autism as a powerful phenomenon: BBC radio play about an autistic 7-year-old girl dying of cancer voted 1 of 10 best radio dramas of all time and sold 35 000 copies of the audio cassette. This study provides an important mirror to enable researchers and clinicians to reflect.


9. This study examined a group of children with ADHD in terms of their social functioning on the Social Relations Scale: identified a subgroup (ADHD–) with elevated scores in the ASD symptom domains and more likely to have oppositional defiant disorder.


A meta-analysis that compares the regional difference in grey matter volume between ASD and controls. Studies used adults and adolescents with Autism Diagnostic Interview Revised diagnosis or DSM IV: case controlled for age, handedness, intelligence quotient and sex. No global differences, but robust differences in various regions, especially amygdala–hippocampus complex. In ASD, medial parietal cortex (precuneus) starting to be implicated in social cognition and processing of the self. Absence of grey matter volume difference between ASD and Asperger consistent with single nosological entity.


A meta-analysis of functional magnetic resonance imaging studies of social cognition between ASD and schizophrenia. Both groups had deficits in the amygdala when attempting to process social stimuli.
Neurodevelopmental and neurocognitive disorders


ADHD children continued to have ToM difficulties as they got older; children with ASD had fewer difficulties.


Average age 19 at diagnosis of Asperger syndrome connected to the onset of personality disorders during adolescence and adulthood. Half cohort met criteria for a personality disorder: two-thirds by men.


This study found Tourette’s syndrome not unitary, proposed a ‘GTS spectrum’ of conditions. Tourette’s syndrome rarely exists in isolation, 90% comorbidity. This study broadens the narrative of neurodevelopmental conditions as ‘spectrum’ rather than single entities.


This study examined the developmental trajectory of prosocial skills (from Goodman Social Development Questionnaire) in n = 57 children from representative longitudinal cohort of children. Ten years of data indicate diagnosis had no effect; social deficits in ASD resistant to typical treatments.


This study compared children with ASD, ADHD and typical development on measures of motor control (e.g. gait), ability to perform and understand gestures. ASD group were more impaired on all measures. Poor understanding and use of gestures linked to social impairment and to compromised proprioception.


N = 89 children and adolescents with ASD, of whom 10% had epilepsy, 18% ADHD, 15% anxiety, 80% sleep disorders and 79% gastrointestinal symptoms. This study found ADHD:AS difference on speed and dysrhythmia; ADHD controls differences on speed and dysrhythmia.


Small study: three n = 12 groups of ADHD, Asperger syndrome (AS) and normal boys aged 8–12, normal intelligence quotient range. Motor function on physical and neurological examination for soft signs measures motor speed, overeit and dysrhythmia. This study found ADHD:AS difference on speed and dysrhythmia; ADHD controls difference on speed and dysrhythmia.


N = 89 ASD males right-handed with 89 matched neurotypical controls. No significant difference in total volumes of white and grey matter; no age-related between-group global changes. Correlation between behavioural variation and regional anatomy: those with more severe autistic symptoms in social and communication had more deficits in occipital cluster; larger grey matter increases in frontal lobe associated with more severe repetitive symptoms.


This study focuses attention away from diagnosis to childhood characteristics that frame treatments. Data drawn from Zuid Holland longitudinal study of 2600 children in 13 birth cohorts: childhood dyssregulation significantly associated with wide range of adult psychopathology.


Data from 47% of all persons with intellectual disability using New York state agencies, of whom 9.7% had ASD: not representative sample. Impulse control, mood dysregulation and perceived threat appeared to underlie most of the aggressive behaviours reported.


N = 31; 74.2% adults with Tourette’s syndrome have impulse control disorder and correlated with tic severity.


Instrument derived from IQF to understand and treat embodied problems.


N = 379 mothers of adolescent and adult children with ASD over 10 years. Larger support networks and fewer stressful life-events associated with fewer depressive symptoms; on average, depressive symptoms increased and covaried with the child’s behaviour problems.


A large multisite US study: sample age 4–18 years. Significant variance in the clinical diagnosis between experienced diagnosticians using same tools. Autism Diagnostic Interview not as useful as previously thought. Cognitive functioning, language and adaptive functioning should be integral to assessment.


Differences in the way data were gathered across the research centres may have biased findings. Discusses how many symptoms should be required to diagnose ADHD as symptoms decline with age and girls report fewer symptoms.