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Guest Editorial

The role of impairment in the diagnosis of autism

Jack Hollingdale, Emma Woodhouse and Quinton Deeley

Summary

Within the medical model, 'impairment' is required for a diagnosis of autism. However, the diagnostic manuals provide limited guidance as to how to interpret impairment, which can impact diagnostic rates and the provision of support. Impairment is discussed within the context of the medical model and current sociocultural landscape.

Keywords

Autism spectrum disorder; autism; impairment; neurodevelopmental conditions; diagnosis/diagnostics.

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The DSM-5-TR[1] and ICD-11[2] require evidence of 'impairment' to meet the diagnostic threshold for autism spectrum disorder, hereafter referred to as autism. Neither manual provides detailed guidance around what constitutes impairment or how to assess this, leading to differing interpretations amongst professionals. In the UK, the neurodiversity movement has gained momentum over recent years, which has influenced the sociocultural landscape surrounding autism and neurodivergence more broadly. Within this changing landscape, many people are questioning the necessity of impairment for a diagnosis. This guest editorial presents some of the current social and clinical discussions about the role of 'impairment' within autism diagnostics. It also highlights the need for further discussions about conceptualisations of expected variation within the general population, and operational definitions of impairment.

Diagnostic impairment

The relationship between diagnostic symptoms and impairment cannot be assumed. Some individuals may have a sufficient number of clinical characteristics required for a specific condition, but not experience the impairment required for a diagnosis. Others may experience substantial functional impairment but not experience the required number of clinical characteristics to meet diagnostic criteria. Therefore, according to current diagnostic manuals, diagnoses should not be based purely on the presence of sufficient clinical characteristics. Accurate assessment of impairment increases the sensitivity and specificity of diagnostic decision-making, and can reduce false positives and overestimation of prevalence rates. These principles may apply to other clinical and psychiatric diagnoses but will be discussed in the context of autism assessment.

Research indicates that compared to non-autistic individuals, autistic individuals experience more 'impairment' (for example, distress and/or difficulties associated with adaptive functioning) and poorer outcomes in specific and/or broader life domains[3]. It should be noted that outcomes measured in research may be based on the expectations of the non-autistic majority and may not reflect how an autistic individual perceives outcomes based on their own values[4].

Nevertheless, there is limited guidance within diagnostic manuals as to what constitutes (current) impairment. For a diagnosis of autism, both manuals require 'significant impairment' across personal, social, educational/occupational or 'other important areas of functioning'. There are no specific guidelines about what counts as 'significant' or which other areas of functioning might be considered 'important'. Interpretations of significance and importance may vary substantially between different diagnosticians, as well as those seeking assessment.

Once an autism diagnosis has been made, the DSM-5-TR provides some limited guidance for differentiating between the three 'dimensional levels of severity': Level 1 ('requiring support'), Level 2 ('requiring substantial support') or Level 3 ('requiring very substantial support'). However, clinical experience and research suggest that the level of support required may change over time and can be strongly influenced by the individual's environment and co-occurring conditions, which are common in autism[5].

The ICD-11 includes a caveat that a diagnosis is still appropriate for individuals who can 'function adequately' through 'exceptional effort'. Again, there is no guidance around what constitutes adequate functioning or exceptional effort. Clinicians assess people with a wide range of functioning and will vary in the weighting they ascribe to different needs, difficulties and attempts to adapt. Confidently and consistently determining the threshold for sufficient impairment can be challenging, especially if some individuals have difficulty identifying and/or communicating their experiences or in situations where environmental demands vary widely (e.g. transitioning from school to university). These differences in clinical judgement may partially explain the variation in diagnostic rates observed across different UK autism services.[6] Inconsistencies in diagnostic thresholds may have significant implications for services and equitable resource allocation.

Impairment may arise for a variety of reasons. Some impairments may result from a mismatch between the autistic person and their environment. For example, workplaces are usually structured around the needs of the non-autistic majority. Therefore, autistic individuals may experience impairment when trying to do their job according to the expectations of non-autistic peers within an environment that does not meet their needs. However, if a workplace is better suited to an autistic individual's needs (for example, flexibility around the work environment, location, hours and forms of communication) this is likely to result in fewer occupational difficulties (see Mandy (2023)[7] for the example of Donald Triplett III). If an autistic individual in a 'reasonably adjusted' workplace has made similar adaptations across different areas of their life, this could reduce the level of impairment below the threshold of significant impairment described in the DSM-5-TR and ICD-11. Therefore, theoretically the same individual could exist within two different environments and (because of the presence or absence of current impairment) meet the medical model's diagnostic criteria for autism in one context but not the other.

Levels of impairment may not be static throughout someone's life. For example, changes in environment and demands, key transitions and/or co-occurring complexities (including both physical and mental health difficulties) may influence the level of impairment at any given time. Hopefully, increased understanding and movement towards more autism-affirmative approaches and environments may have an impact on autistic people's experiences of impairment. In theory, a society that meets the needs of autistic individuals by person-centred adjustments should lead to a reduction in environment-related impairment. However, some impairments may still exist in spite of comprehensive efforts to adjust an autistic individual's environment.

In some cases, impairment may be because of specific autistic differences. For example, someone might want to vary an aspect of their daily routine but feel unable to do so because the change would result in too much uncertainty and distress. Another example could be someone having an unusually high pain threshold because of sensory processing differences, which leads to a physical injury not being treated in a timely manner. In the future, assuming environmental adjustments for people with autism become commonplace, difficulties resulting from specific autistic differences that are less responsive to environmental adjustment may be the more frequent cause of impairment.

Recent research has also developed our understanding of the role of 'camouflaging', also known by other terms, such as 'masking' or 'adaptive morphing'. Camouflaging describes a range of behaviours used by autistic people to appear less autistic in social interactions in predominantly non-autistic environments. It is often an attempt to avoid the effects of stigma and intolerance directed towards autistic people, and is associated with exhaustion, anxiety, depression and suicidality.[8] Camouflaging may mask impairment for some individuals to such a degree that they no longer meet criteria for autism when using the DSM-5-TR, although they may still meet diagnostic criteria when using the ICD-11, if these practices constitute 'exceptional effort'. In this case, the exceptional effort becomes the required impairment for a diagnosis. As previously stated, in the absence of more concrete guidelines, what constitutes exceptional effort will be a matter of clinical judgement for each diagnostician – while recognising the inherent difficulty of making such judgements. Camouflaging may also affect negatively mental health and overall well-being.[8]

While some individuals engage in strategies that reduce impairment, others may present with qualitative characteristics of autism without having experienced significant impairment before or at the time of their assessment. Effective compensatory skills and/or an environment that is well matched to the person's strengths and support needs may mean that impairment has not manifested by the point of assessment and may not in the future. According to the DSM-5-TR and ICD-11, the absence of impairment means that these individuals would not receive an autism diagnosis.

In theory, if the individual's environment changes (for example, the transition from primary to secondary school) and new demands exceed their capacity to cope (producing evident impairment), they would then meet the full criteria for autism. Therefore, a young person may not technically meet diagnostic criteria for autism because of the absence of impairment but be diagnosed as autistic later in life when demands increase and impairment becomes present. This can cause confusion, as autism is a neurodevelopmental condition that (diagnostically) is present across the lifespan. This presents both clinical and conceptual challenges. For example, clinicians may perceive an ethical quandary whereby they are unable to diagnose autism using the DSM-5-TR or ICD-11 because of the absence of impairment at the time of their assessment but foresee likely impairment when demands are likely to exceed capacity. Non-diagnosis of autism in a person with clear autistic characteristics may require a re-referral to services to acquire a diagnosis at times of crisis or difficulty in the future, contributing to delays in accessing support and additional expense in meeting their needs.

One way in which clinicians may approach this is to acknowledge the presence of autistic characteristics but not give a diagnosis of autism, as the diagnostic criteria have not been met. Given that each individual characteristic in the diagnostic criteria for autism is transdiagnostic (and can also be seen in the general population), it would not be sufficient to identify one or two behaviours and conceptualise these as 'autistic traits/characteristics'. For example, qualitative differences in eye gaze could be present in the context of ADHD, anxiety, psychosis or depression, or in the absence of any neurodevelopmental/mental health condition. However, if there is a cluster of qualitative characteristics across different domains in the diagnostic criteria for autism, but these are 'subthreshold' for diagnosis (e.g. there is no impairment), clinicians may opt to describe these as 'autistic characteristics'. Some argue that this should be conceptualised as 'autistic spectrum condition' rather than 'autistic spectrum disorder'. The autistic traits/characteristics would then be discussed in the clinical formulation and recommendations, including acknowledgement that the presence of autistic characteristics is a risk factor for adaptive problems and/or coexisting mental health problems, which may justify additional support as personal circumstances and demands change.

Most clinicians are likely to agree that it is better to work preventatively to ensure that individuals do not reach a point of crisis before they are able to access a diagnosis. Therefore, clinical judgement may require diagnosticians to take the overall situation into account when determining whether a diagnosis is appropriate. Clinical judgement is an essential feature of the autism diagnostic process because of variations in individual circumstances. Rightly or wrongly, a low threshold for assigning a diagnosis of autism may contradict the diagnostic criteria as applied by others but may negate the need for lengthy and costly reassessments later in life. Further discussion to inform greater consistency in the application of clinical judgement within autism diagnostics would be helpful, not least for reasons of equity and the coherence of the construct as it is applied in clinical practice.

Changes in conceptualisation

In recent years there has been a move away from the perception of autism as a 'disorder', and an increased emphasis on 'strengths' and 'differences' rather than 'weaknesses' and 'deficits'. While this change in language may more accurately reflect some people's experiences of autism, the rejection of autism as a disorder contradicts the medical model approach of the DSM-5-TR and ICD-11. A difference in neurotype may not require additional provisions, whereas a disorder (as defined by the diagnostic manuals) implies that there is impairment, and that support is required. A move away from the medical diagnostic paradigm has potential implications for identification and provision of support, particularly given limited resources. If an individual is identified to have a different neurotype rather than a disorder, support needs (assuming they are present) may go unrecognised and unmet.

More recently, some individuals have advocated for the self-diagnosis of autism to be recognised. This is perhaps not surprising given the length of National Health Service (NHS) waiting lists and the cost of private autism assessments. Within such a paradigm, the diagnostic need for impairment is negated. Recognition of self-diagnosis may lead to a broader and less consistent definition of autism prevailing across society. While self-diagnoses may have individual and social benefits (for example, helping the self-diagnosed to make sense of experiences and feel understood/accepted), an 'official' diagnosis may provide access to a much broader range of support and additional benefits.[9] Equally, self-diagnoses carry risks of misdiagnosis. Misattributing difficulties/characteristics to autism when they may be better accounted for by another diagnosis could misdirect individuals away from seeking potentially beneficial care.

What next?

Given inconsistencies in the assessment of impairment and changes in the conceptualisation of autism, this editorial calls for further discussion by autistic individuals, families and professionals to better understand impairment. It is also important to have more clarity around differences between clinical features relevant to the autism diagnosis and characteristics that are part of *expected* variation within the general population. Developing a consensus on an operational definition of impairment may help to improve international diagnostic reliability and consistency. This consensus should be developed using mixed method research involving clinical expertise and a broad range of lived experience, as well as considering cultural differences.

Within the UK, diagnosticians are currently bound by the DSM-5-TR and/or ICD-10/11 criteria for autism, both of which require the presence of impairment. These manuals provide limited guidance as to how to interpret impairment, potentially contributing to variable diagnostic rates across different services. In the UK, many health, education and social care services are structured around the medical model. The implications of moving away from this model (and in particular, the requirement of impairment for diagnosis) need to be carefully considered. Diagnostically, impairment may be used to differentiate between individuals with autistic characteristics who do require some form of support, and those who do not. It also informs which interventions would be most appropriate for the individual or their environment following their diagnosis. The failure to identify impairment would therefore raise the question of the basis on which resources should be allocated to people with autistic characteristics, and what type of treatment or support should be offered. Further discussions are required to approach a consensus as to how to manage the assessment of impairment in this evolving landscape.

Jack Hollingdale, Department of Forensic & Neurodevelopmental Sciences, Compass Psychology Services, London, UK; **Emma Woodhouse**, Department of Forensic & Neurodevelopmental Sciences, Compass Psychology Services, London, UK; and Institute of Psychiatry, Psychology and Neuroscience, King's College London, UK; **Quinton Deeley**, Institute of Psychiatry, Psychology and Neuroscience, King's College London, UK; and National Autism Unit, South London and Maudsley NHS Foundation Trust, London, UK

Correspondence: Jack Hollingdale. Email: jack.hollingdale@compasspsy.co.uk.

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