

Commentary: Challenges and opportunities in autism assessment – a commentary on Kanne and Bishop (2020)

Malcolm MacLachlan^{1,2} 

¹ALL Institute and Department of Psychology, Maynooth University, Maynooth, Ireland; ²OUSHI, Palacky University Olomouc, Czech Republic, Czechia, Europe

The challenge of ASD assessment and diagnosis

While some argue that the diagnosis of autism itself – across all age groups – lacks validity (Waterhouse, London, & Gillberg, 2016), others question the validity of commonly used psychometric instruments. For instance, Conner, Cramer, and McGonigle (2019) explored the predictive validity of ASD measures against clinical diagnosis. Using sensitivity, specificity and area under the curve (AUC) analyses to assess accuracy of psychometric instruments, they found that the top performing instrument was ‘fair at best’, while the poorest ones were not predictive of a diagnosis at all. They thus concluded that ‘none of these measures are very accurate’ (p. 1). Penner’s, Anagnostou, Andoni, and Ungar (2017) review of the health professionals and psychometric tools recommended for the ‘diagnostic assessment’ of ASD across different professional organisations and jurisdictions, found that these varied considerably in terms of professional qualifications of practitioners, instruments or procedures used, and the time required for the assessment. In practice, therefore there appears to be little consistency in the approach taken to assessment. Indeed, they state that ‘There was little supporting evidence for team and personnel recommendations’ (p. 517); that is who should be involved in actually doing assessments and what sort of skill set they required. In a separate but cogent review, Hayes’s, Ford, Rafeeque, and Russell (2018) review of twenty-one guideline documents reported that they ‘varied in recommendations for use of diagnostic tools and assessment procedures’ (p. 1). Hayes et al also stressed the importance of considering social factors ‘but there were few concrete recommendations as to how these factors should be operationalized for best diagnostic outcomes’ (p. 1). Furthermore, they state that ‘We would not recommend greater rigidity within CPGs [Clinical Practice Guidelines] when *evidence for best diagnostic practice is inconsistent*’ (p. 23; italics added). In not recommending ‘greater rigidity’, they are recognising that there is an insufficient database to guide or mandate practitioners to use specific assessment practices.

Currently, access to services in many countries is often front-loaded by very detailed assessments to

provide a diagnosis. Sometimes a very detailed assessment will be necessary and justified. In some health systems (such as Ireland, where the current author is based), this ‘front-loading’ of time into assessment and diagnosis clearly displaces resources from intervention, lengthening the accompanying waiting lists which Kanne and Bishop (2020) are rightly eager to reduce. Their call for retaining the high ‘quality’ of assessment is laudable, but I am concerned that in practice a number of conceptually related issues may be confused with ‘quality’. First, as some cases are clearly more complex than others, it follows that some should be easier (and shorter) to assess, than others – the *time* it takes to conduct an assessment is not necessarily related to the quality of the assessment. Second, an efficient system would use *tiered* assessment depending on the complexity of presentations, in order to carry out assessments that are tailored to the extent of complexity; recognising that one approach does not fit all, and the same degree of assessment is not necessary for all. Third, when referring to quality, often a standardised approach is promoted as best practice and taken to imply a uniform approach to assessment. However, a *standardised* approach is one that reaches a certain standard; (this could be in terms of the qualifications of the assessor, the time spent with the client, the reliability of the instruments used for assessment; or the requirement to combine observational, interview and psychometric findings) while a *uniform* approach is unvarying, everybody getting the same (there is little scope to adapt the assessment to the person being assessed, or to the behaviours they may present with). This difference, between a standardised and a uniform approach, is the difference between equity and equality, and it is about fairness. In the context of limited resources (which exists everywhere including in the wealthiest countries), providing a uniform service, almost certainly guarantees that many people will be denied the same level of opportunity based on a detailed assessment; some will have to wait much longer (this can sometimes run into years and create ‘secondary’ conditions), and some may not get assessed at all. Fourthly, *intensity* of assessment

and *comprehensiveness* of assessment are also often conflated with quality. Intensive assessment may focus on some areas of functioning, but not all; while comprehensive assessment may address all, or nearly all areas of functioning, but not necessarily in much depth. It should rarely be necessary to have a comprehensive and intensive assessment; and a uniform approach is unlikely to achieve the same standard of assessment for all. Thus, researchers and practitioners should consider 'quality' in the context of assessment very carefully, as it may be used ambiguously rather than scientifically, and suggestions of a lack of quality in assessment may unnecessarily and unjustly concern already worried and stressed families. Furthermore, assessment should not be seen as a one-off event; rather, it should be an ongoing process, alongside interventions, as clinicians understand better how to assist people with ASD, or other conditions.

The distribution of resources

It is clear that early identification of behaviours characteristic of ASD (such as social impairment, restrictive repetitive behaviours and atypical sensory responsiveness) is critical, so that timely interventions can address these and prevent further difficulties developing. While there is no international best practice per se, a thoughtful, systematic approach to assessment, using some or all components of well-developed instruments, careful history taking, observation and interviews, is necessary. However, the reification of such assessment is problematic, not just for the reasons mentioned above, but also because we live in a world of finite resource. New approaches may allow us to make better use of our limited resources.

Kanne and Bishop's (2020) suggest that as a parallel to assessment for ASD, cancer assessment would not be entrusted to new technology, such as artificial intelligence. In fact, that is exactly what is now happening, with AI proving to be as accurate as the combined judgement of two experienced radiologists (McKinney, 2020); the algorithms will improve, human judgement probably would not. We should explore the use of technology for assessment or intervention, recognising that psychometrics is itself a technology. The use of technology also has great potential to extend assessment and intervention to people – particularly in low-income countries – who simply have no other means of accessing such services (see, e.g., Hamdani, Minhas, Iqbal, & Rahman, 2015).

Kanne and Bishop (2020) also question if, in other disciplines, less well-qualified cadres would be asked to undertake tasks comparable to ASD assessment. The principle of task-shifting is in fact the corner-stone of the World Health Organization's approach to public health (in high-, medium and low-income countries) and is as relevant and

effective in psychosocial services (Deimling Johns, Power, & MacLachlan, 2018) as it has been shown to be across a swath of other health contexts (European Commission, 2019). We therefore need to consider both technology and other cadres and creative possibilities between the two, if we are to address the inequitable and inadequate access to child and adult services, both within very rich countries, and globally. This will, for sure, challenge and change the psych professions (Susskind & Suskind, 2016). By being part of this change, those with great expertise – such as Kanne and Bishop – can help shape that change, creating a more equitable and inclusive system with greater coverage.

The COVID-19 situation has demonstrated just how much families need ongoing supports and interventions. Here, too, a more flexible approach has been needed, taking account of social distancing, the use of personal protective equipment and infection control procedures; and at times using other personnel, digital and assistive technologies. A prior global review of services and supports for children with developmental delays and disabilities concludes that 'Parents and caregivers who receive training in psychosocial interventions and ongoing support can help children with delays and disabilities thrive in context' (Collins et al., 2017). I would like to suggest that increasingly the question should not be 'what is best practice?' but rather 'what is sufficient to provide the services needed, in a fair way, to the range of people needing them, within the resources available?'. This latter question is surely just as scientifically demanding and practically challenging a question as the former. In fact, this is what we should be asking longer term to increase access to assessment and intervention. While we should certainly continue petitioning for more resources, we also need to recognise that so too will others continue to petition for more resources, in cancer, dementia, community living, and so on. So, we also need to better allocate the resources we have to tackle the challenges we face.

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Correspondence

Malcolm MacLachlan, Department of Psychology, Room SF12, John Hume Building, North Campus, Maynooth University, Maynooth, Ireland; Email: mac.maclachlan@mu.ie

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