EXAMINING DIAGNOSIS:

A sociological view of autism assessment

A BRIEF REPORT FOR HEALTHCARE PROFESSIONALS

Sheila Mahon

SUMMARY

Our research at the University of Exeter aimed to explore autism diagnosis in secondary care and, in particular, to understand how healthcare professionals collaboratively make diagnostic decisions when assessing individuals coming for an assessment of autism.

We observed assessment discussions in four specialist autism assessment teams[1] in the south of England across children's, young people's and adult services. We also interviewed healthcare professionals involved in autism assessment from a range of professional disciplines and looked at clinical guidelines relevant to autism diagnosis in the UK.

WE FOUND THAT:

- Specialist autism assessment teams are **structured differently from each other**, have different purposes (e.g. diagnosis, formulation or more general discussion) and involve different types of professionals dependent on local resources.
- **Clinical guidelines vary** in their recommendations, so assessment can be shaped by local expertise and conditions and therefore vary across regions.
- **Making diagnostic decisions** about people who come for assessment can be challenging, due to the heterogeneity of symptoms, the necessity of interpreting behaviours that may be ambiguous, and a lack of clinical biomarkers.
- **Uncertainty** is a characteristic of decision-making, especially with cases that are complex, borderline, or involve potential co-conditions.
- Team members value greatly the **multidisciplinary context** within which they make decisions, and welcome different perspectives on a case.
- This range of perspectives helps them to 'make sense' of sometimes contradictory evidence, and create a **diagnostic narrative** or story that incorporates all aspects of the evidence.
- **Services are under pressure**, with a large number of referrals leading to long waiting lists and stretched resources.

[1] We have not used the term 'MDT', although most of our observations were of multi-disciplinary working, however one team was made up entirely of clinical psychologists.

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IMPLICATIONS FOR PRACTICE

- The pressure on autism assessment services means that teams often feel under-resourced to manage the complex and time-consuming process of autism assessment. We support other research, therefore, which identifies that the process of autism assessment in England is one that does not currently fully meet the needs of patients and families. This pressure is felt by healthcare professionals at the sharp end of diagnosis. This can impact on how assessment happens, for example, in limiting school observations or allowing time for full formulation discussions, as well as lack of access to a full range of professional roles within the team.
- A diverse range of professional roles from nursing, social care, clinical and psychological backgrounds can help to ensure an assessment includes different perspectives, but resources do not always allow this. Some meetings are more multi-disciplinary than others, and given how helpful team members find different professional views, we would recommend that teams should be better resourced to include a range of perspectives to get the best out of meetings.
- A greater understanding in wider society of the complexity of assessment may help diagnostic communication between healthcare professionals and patients and ease some of the tensions felt by patients and families coming for diagnosis, which are created through the system itself. This includes the understanding that diagnosis is not only about 'scoring' on specialist tests, and that tests themselves have limitations.
- The rationale for creating a specialist autism pathway has benefits in terms of clarity of process and development of clinical specialisms. However, some clinicians suggest that this can bring challenges. A separation from broader health assessments, it is argued, can have a negative effect in inhibiting a holistic approach to assessing an individual for a range of complex needs. We suggest that an examination of the benefits and drawbacks of specialist autism assessment services, the resources they require to operate effectively, and how they operate in the context of wider health services, would be appropriate and timely.

Frank Allen

OUR STUDY IN MORE DETAIL

Our research aimed to explore autism diagnosis in secondary care and, in particular, to understand how healthcare professionals collaboratively make diagnostic decisions when assessing people who come for autism assessment. The study draws on the sociology of diagnosis, which argues that diagnosis cannot be separated from wider influences of human agency and deliberation (1). A sociology of diagnosis approach challenges the taken-for-granted fit of diagnostic categories to their conditions and instead considers them as socially framed and shaped by wider social forces and interaction (2). For example, some studies show that social factors such as individual patient preference, availability of resources, or local organisational factors can shape diagnostic practice in, for example, heart disease (3). We were, therefore, interested in how the process of autism assessment itself may impact on decision-making.

We set out to explore what kinds of 'social factors' may be present in autism diagnosis. Our findings suggest that autism diagnosis is not a straightforward, linear, clinical process Healthcare professionals have to 'find' autism in an individual, and yet this individual's behaviour, and the assessment of it, is in itself a social process, shaped by locally available resources and expertise, the interaction between families and healthcare professionals, and between healthcare professionals themselves.

Our review of clinical guidelines for autism assessment in the UK found that recommendations for best practice are not consistent across guidelines. This means that how guidelines are used will be shaped, at least in part, by local expertise and resources, as well as by the role and expertise of the healthcare professionals involved in assessment. We found a number of **contextual, interactional and operational factors** in the guidance that might influence how assessment can happen locally. However, one consistency across guidelines was that multi-disciplinary team working is considered to be'gold standard', but there is little guidance on how that should work in day-to-day clinical practice.

In our observation of specialist autism assessment teams we found great variation in how the multi-disciplinary aspect of autism assessment works in practice, including team make-up, frequency and purpose of meetings as well as meeting structure. We found that, particularly in threshold cases, making clear diagnostic decisions is challenging.

JA Tan

Nicole Ayala

HOW DO HEALTHCARE PROFESSIONALS DEAL WITH DIFFICULT DECISIONS?

To manage challenging decisions, team members often have extended discussion around threshold cases, and are able to find a **diagnostic 'narrative'** that makes sense, even when evidence is contradictory. This is especially important if the decision is in contradiction to the ADOS[2] score.

We observed that experienced healthcare professionals use what they term a **'feel' of autism** to aid discussion. Even if difficulties are not being reported by the patient, or if the ADOS score is under-threshold, they express an ability to have a 'sense' that someone has autism, based on their previous clinical experience and judgement. This can help when discussing a challenging case.

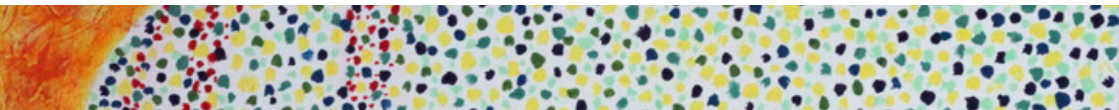
Team members also make decisions about whether the individual is **masking** autism symptoms, and they do this by considering a range of complex factors including the **motivation** of the patient or family and the way in which they recall their experiences.

Team members also take a **pragmatic approach** to diagnosis. They consider social outcomes for the patient and family and often discuss what might be helpful, especially when uncertain.

Team members can **present information and ask questions of each other** in ways that can help to facilitate discussion and encourage participation in the assessment meetings[3]. Developing equal and respectful working relationships between team members, across professional roles and hierarchies, is important to enable full and transparent assessment discussions.

[2] Autism Diagnostic Observation Schedule

[3] Hayes J, Russell G. "Saying it out loud": Collaboration and professional roles in autism assessment teams. Manuscript in preparation. 2021.



JA Tan

James Frye

WHAT DID HEALTHCARE PROFESSIONALS SAY?

In our **interviews with healthcare professionals**[4], we found, in line with other studies, that autism assessment teams are under a great deal of pressure, with long waiting lists and lack of post-assessment services, especially for adults. Healthcare professionals express concern about the increasing number of people being referred for autism assessment.

Team members find diagnostic tools such as the ADOS useful: but only in the context of other kinds of assessment processes. This means that sometimes the results of the ADOS are over-ruled, particularly if they believe that the individual has developed strong coping or 'masking' skills. Healthcare professionals are particularly aware of this issue when assessing women and girls. With threshold cases, diagnosis is sometimes uncertain and they consider that behaviours could be due to other reasons such as anxiety or family difficulties, and this is sometimes difficult to pull apart. Overall, healthcare professionals see the purpose of diagnosis as a way to understand, or make sense of a person's difficulties.

HOW USEFUL IS THE ASSESSMENT TEAM MEETING?

Generally healthcare professionals find assessment team meetings extremely helpful as a way to share different views and results of assessments, tease out difficulties, especially in threshold cases, and use meetings as a forum to share concerns and uncertainties. However, all teams are time-pressured, and sometimes it is challenging to carve out time for good discussion or have all team members present.

We found that teams operate differently according to local needs, resources and expertise. Case discussions in meetings vary in structure across teams, with some teams presenting full and detailed reports of each assessment and others taking a more flexible and interactive 'information-sharing' approach. We found that healthcare professionals use different types of questions to seek clarification or new information and to invite participation from other team members. These questions, and the team meeting structure, can serve to encourage collaboration or, conversely, inhibit discussion, thereby impacting on collaborative working.

[4] Hayes J, Ford T, McCabe R, Russell G. "Not a precise art": Social factors and the diagnosis of autism. Under review. 2021.

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IF YOU'D LIKE TO KNOW MORE

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THANKS AND CREDITS

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