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A national study to investigate the clinical use of standardised instruments in autism spectrum disorder assessment of children and adults in Scotland

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ABSTRACT

Background: There are few large scale studies about the nature and extent of the actual use of standardised assessments for Autism Spectrum Disorder diagnosis in clinical practice. This study compares and contrasts practice in diagnostic services for both adults and children.

Method: We conducted an analysis of retrospective case notes from 150 cases (70 adult, 80 children) assessed for Autism Spectrum Disorder by 16 diagnostic services.

Results: We found differences between adult and child services in staff training and use of standardised assessment during diagnosis. All child services had staff trained in and regularly using standardised assessments. Most adult services had staff trained in using instruments but only half used them regularly. Administration of standardised ASD assessments was ten times more likely in children than in adults (OR = 10.1; CI = 4.24, 24.0). Child services selected the ADOS as the standardised tool and adult services selected the DISCO, with very little overlap. Decisions to administer standardised tools were not based on case complexity but rather the same process was applied to all referrals within a service. The three recommended components of assessment (clinical history, clinical observation and contextual information) were included for the majority of cases, although clinical observation was more frequently used with children than with adults.

Conclusions: Based on the findings, we suggest a need for a wider range of appropriate assessments for use with adults, particularly those with an intellectual disability and for further research into the reasons behind the choices clinicians make during the assessment process. For child services in Scotland, there is a need for more training in use of current diagnostic interviews. Clinicians did not vary tools used based on complexity, suggesting that this is a notion still to be clearly defined and operationalised in clinical decision making about the use of standardised assessments.

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1. Introduction

There is no single diagnostic measure for Autism Spectrum Disorder (ASD). Experienced clinicians observe core symptoms and interpret information from a range of sources, with consideration of age, intellectual ability and co-existing conditions (Matson et al., 2012). Standardised instruments structure this information gathering, making it more reliable and consistent between cases (De Bildt et al., 2004).

The components of a 'gold-standard' ASD diagnosis and the usefulness of standardised instruments for this task are much debated and only limited guidance exists for clinicians in terms of assessment processes and tools. Charman and Gotham (2013) summarise the commonly recommended standardised ASD diagnostic instruments for clinical history and observational assessments for adults and children. These are: the ADOS (Autism Diagnostic Observation Schedule, Lord et al., 2000); ADI-R (The Autism Diagnostic Interview-Revised, Lord, Rutter, & Le Couteur, 1994) and The Developmental, Dimensional and Diagnostic Interview (Skuse et al., 2004). The DISCO (Diagnosis of Social and Communication Disorder Schedule, Leekam, Libby, Wing, Gould, & Taylor, 2002) is recommended for use in complex cases for adults (NICE 142, 2012). For the purpose of this paper, screening instruments such as the M-CHAT (Kleinman et al., 2008) are not included and there was no reported use in our clinical sample of children aged between 0 and 5 years (n = 23/70). Diagnosing clinicians are advised to consider using autism specific standardised instruments as part of a more comprehensive assessment for children and young people but not in every case (National Institute for Health and Clinical Excellence (NICE), 2011; Scottish Intercollegiate Guidelines Network (SIGN), 2007) and in more complex cases for adults with and without a learning disability (NICE, 2012).

It has been argued that a thorough clinical history alongside an astute clinical examination can be an excellent alternative to standardised assessments (Carpenter, 2012). However, research based on application of DSM – IV diagnostic criteria (American Psychiatric Association, 1994) highlights that there can be low levels of diagnostic agreement between expert clinicians without the use of standardised instruments (Williams, Atkins, & Soles, 2009) and that a combination of two or more standardised assessments can increase reliability of diagnosis in children (e.g. Kim & Lord, 2012). Staff training in the use of screening tools has been shown to increase expertise and diagnostic agreement in paediatric practice (Swanson et al., 2014). It is recommended in the National Autism Plan for Children [NAPC] (Le Couteur, Baird, & Mills, 2003) that in child services, at least one clinician in each area should be trained in one of the current diagnostic interviews and that staff should be trained in one of the currently recommended assessment tools, which could include observational tools. It remains unclear, however, how widespread the staff training in standardised diagnostic instruments is.

Evidence-based clinical guidelines recommend that experienced clinicians should make ASD diagnoses using all three components of assessment: information from a clinical history; clinical diagnostic observation and contextual assessment, i.e., the individual's presentation in real life settings (NICE, 2011, 2012; SIGN, 2007). The latter can be addressed by direct observation outside the clinical context, or questionnaires completed by informants observing the individual in different contexts.

There has been limited research exploring the extent to which clinicians pragmatically balance the recommendations relating to use of standardised assessment within a context of scarce clinical resources and a need for efficiency (Matson et al., 2012).

In child services, earlier studies indicated that standardised instruments are used in 33–61% of cases (Martin, Bibby, Mudford, & Eikeseth, 2003; Palmer, Ketteridge, Parr, Baird, & Le Couteur, 2010; Williams et al., 2009;). Two recent studies found that the Autism Diagnostic Observation Schedule (ADOS; Lord et al., 2000) was used in around half of cases and that its use was more likely with older children and in more complex cases (Hathorn, Alateeqi, Graham, & O'Hare, 2014; Rzepecka, McKenzie, McClure, & Murphy, 2011).

Very few studies have reported clinician views about practice in ASD diagnostic assessment. In a survey of 116 practitioners from child and adult services (Rogers, Goddard, Hill, Henry, & Crane, 2015), 75% found standardised instruments to be very or quite helpful. Only 4% found them to be unhelpful. In their study of reported rather than actual use, the ADOS and the DISCO were the most commonly used tools across all services, with 63% reportedly using ADOS and 33% using the DISCO. How this differed across child and adult services was not reported.

In recognition of the importance of the clinician perspective on selection and use of standardised instruments, our research team carried out focus groups with staff (n = 95) from all 16 participating services. Findings reported in Rutherford et al. (submitted for publication) identify challenges and solutions to reducing the wait for diagnostic assessment. All child services viewed the ADOS positively and suggested that even when not using it, familiarity with the structure informs assessment practice. Child teams reported feeling well trained and confident in diagnostic assessment, whereas in adult services there was variability between well established and newer teams. Several less experienced participants reported taking on ASD diagnosis despite not having had enough relevant training only because no other service would take this role on. More experienced adult teams reported confidence that clinical judgement exceeds that of such tools and were less motivated to use them clinically even if trained.

There have, however, been no studies of the actual use of standardised instruments in clinical practice with children and there are no studies in adult services. The present study, therefore aimed to identify, from a sample of Scottish child and adult ASD diagnostic services, (1) the number of services with at least one clinician trained in the use of a standardised instrument for ASD diagnostic assessment, (2) the extent to which standardised instruments are used in practice, and (3) the extent to