ELIZABETH KENT BSc (Hons)

USING THE AQ-10 WITH ADULTS WHO HAVE A BORDERLINE OR MILD LEARNING DISABILITY: PILOT ANALYSIS OF AN ADAPTED AQ-10

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Overview of the Major Research Project

Section A introduces issues related to the practice of case identification and assessment of Autism Spectrum Disorder (ASD) in adults who have a learning disability (LD). The review identifies and critically explores screening and assessment measures used to identify or diagnose ASD symptomatology in adults with learning disabilities. Findings from ten papers are presented with the review focusing on psychometric findings. Outcomes regarding the appropriateness of the screening and diagnostic tools identified are examined with implications for future clinical and research practice highlighted.

Section B consists of an empirical investigation to explore the use of the AQ-10 questionnaire with adults who have a borderline or mild learning disability. A mixed-methods approach is used to explore experts by experience's understanding of the questionnaire. The questionnaire is then redesigned following measure development principles to produce an adapted measure, which is then piloted to obtain some initial psychometric properties. Results are from the adapted measure are compared to results from the un-adapted measure and findings are discussed. Part B concludes with a discussion regarding limitations and implications.

Table of Contents

Section A: The Screening and Diagnosis of Autistic Spectrum Disorder in Adults with a Learning Disability - Review of Screening and Diagnostic Tools

Section B: Using the AQ-10 with Adults who have a Borderline or Mild Learning Disability: Pilot Analysis of an Adapted AQ-10

List of Tables

List of Figures

Appendices

Running Head: A REVIEW OF SCREENING AND DIAGNOSTIC TOOLS

Section A: The Screening and Diagnosis of Autistic Spectrum Disorder in Adults with a Learning Disability - A Review of Screening and Diagnostic Tools

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Abstract

Background and aims: Learning Disability (LD) and Autism Spectrum Disorder (ASD) frequently co-occur. Early identification and accurate diagnosis leads to better outcomes and access to treatment, improving quality of life, yet there are few identification and diagnostic tools that have been developed for adults in this population. The aim of the current literature review was to identify and critically evaluate possible screening and assessment tools to identify or diagnose ASD symptoms in adults with a learning disability. **Methods:** Electronic databases were searched (1900-present). Ten studies were included in the review. Of these, four screening tools and three assessment tools were identified and critically appraised. To date, these studies have not been critically appraised in a review. **Results and conclusions:** For the screening tools, the SCQ may be appropriate for individuals in the mild or borderline LD range whereas the PDD-MRS or DiBAS-R may be better for individuals in the moderate or severe ranges. For diagnostic tools, the ADOS and ADI/ADI-R had poorer psychometric properties when being used for this population. The ASD-DA had good properties but was unable to differentiate ASD and PDD-NOS. **Implications:** findings suggest a need for more research and replication of instruments with a move away from a 'one size fits all' approach to the identification and assessment of autism in adults with a learning disability. The findings are discussed in relation to NICE guidelines and implications for future research.

***Keywords*: Learning Disability, Autism Spectrum Disorder, Intellectual impairment, Screening, Case identification, Diagnosis, Assessment.**

1. Introduction to the Autism Spectrum

1.1 The Historical Perspective

The term 'autism' had its origins when Kanner first used the label in describing case histories of children who shared unique similar patterns. He noticed these children all displayed difficulties in relating to others and exhibited "extreme autistic aloneness" (Kanner, 1943, p.242). Later, in the 20th century autism was understood from a mental health perspective, with terms being used to describe symptoms as "psychotic" or "schizophrenic reactions" (APA, 1968, p.28). In 1980, the Diagnostic and Statistics Manual of Mental Disorder – 3rd Edition ([DSM-III], APA, 1980) represented a departure from this understanding and defined autism in part by the absence of psychotic symptoms, labeling the disorder as Pervasive Developmental Disorder (PDD); a term which was further separated in 1987 into PDD-not otherwise specified (PDD-NOS) and Autistic Disorder (APA, 1987). This trend of separating the different symptoms associated with autism continued in subsequent editions of the DSM when in 1994 a polythetic definition of autism was adopted to include labels such as PDD-NOS, Asperger Disorder (AD), Rett's Syndrome and Childhood Disintegrative Disorder (CDD) (APA, 1994).

1.2 Present Definition, Prevalence and Classification of Autism

Classification of autism has undergone many changes and as such, will always be under contention. Autism is now largely described as a set of heterogeneous neurodevelopmental conditions that are characterised by difficulties in social communication, social interaction and restrictive and repetitive behavior, interests or activities (RRBIs) (Lai, Lombardo & Baron-Cohen, 2014). The most recent revision of the DSM (DSM-5) published in 2013 (APA, 2013) is a move away from defining Autism via subtypes and instead adopts and umbrella term of Autistic Spectrum Disorder (ASD). In other words, although it is

acknowledged that there is a wide variation of severity and characteristics of ASD, the new classification sees ASD as dimensional in nature, using one diagnostic term rather than multiple labels. These changes potentially mark a significant impact for services and service users alike (*see* McPartland, Reichow &Volkmar, 2012 for a review).

At present, it is unknown how the new criteria will affect prevalence rates (Lai, Lombardo, Auyeung, Chakrabarti & Baron-Cohen, 2015) but nevertheless, ASD remains the most diagnosed neurodevelopmental disorder in the United Kingdom (Baron-Cohen et al., 2009). Recent estimates put the median worldwide prevalence of autism at 0.62-0.70 per cent (Elsabbag et al., 2012; Fombonne, Quirke & Hagen, 2011) with an estimated prevalence of 1-2 per cent for adults (Brugha et al., 2011). Although the prevalence rate for ASD has significantly increased over time (due to changes in improved awareness, identification and changes to the diagnostic criteria rather than an increase of ASD per se, Baird et al., 2006), the pattern of it being more diagnosed in males has been constant, with current ratios estimated at 4:1 (Fombonne, 2003).

1.3 Comorbidity

Matson and Shoemaker (2009) state that individuals with ASD are also likely to have a learning disability (LD). A 'learning disability' (LD) is a term used to refer to a reduced capacity to understand information and cope independently (Department of Health [DoH], 2001) and is a term used uniquely in the United Kingdom (O'Brien & Kumaravelu, 2008). The phrase is synonymous with 'intellectual disability', which is preferred internationally. The British Psychological Society (BPS, 2000) state that to meet criteria for an LD the individual must have an impairment in adaptive functioning (i.e. daily living skills) and a full scale intelligence quotient (IQ) below 70, with both of these occurring prior to adulthood.

The DSM-IV criteria separate LD into categories according to severity. A profound or

severe LD is characterised by an IQ below 40 where the cause is thought to be medical (often chromosomal or prenatal) (Hagnerg & Kyllerman, 1983). A moderate learning disability is characterized by an IQ of between 35 to 55 where both medical and background psychosocial factors play a role (Gillberg & Soderstrom, 2003). An IQ in the range of 55 to 70 represents a mild learning disability. Additionally, an IQ range of 70 to 84 has been classed as a Borderline LD where individuals have been shown to be at high risk of developmental, academic and behavioural problems (Goodman, 1995).

Prevalence rates of comorbid LD and ASD vary, which could be because of different factors including dissimilar sample types (e.g. children versus adults), different assessment methods of identifying ASD and different definitions of autism itself. Despite this, estimates range from 40% of individuals with LD having ASD and 70% of individuals with ASD having LD (LaMalfa, Lassi, Bertelli, Salvini & Placidi, 2004).

In terms of nosology, ASD symptoms can vary with severity of IQ. For example, findings reveal that lower IQs are associated with a higher reported rate of stereotypies (Bartak & Rutter, 1976). Furthermore, RRBIs are more common in those with ASD and LD rather than ASD alone. Finally, some report that the more severe an individual's LD, the greater the likelihood of ASD occurrence (Vig & Jedrysek, 1999; Matson & Shoemarker, 2009).

Despite the relative paucity of research in these issues of comorbidity, current studies do suggest that the presentation of ASD in those who have an LD is qualitatively different from the symptomatology of ASD in persons with IQs in the normal range (Maton & Shoemaker, 2009). Thus, those in the autism spectrum who have an LD are described as having dissimilar needs from those with LD or ASD alone (Carminati, Gerbe, Baud & Baud, 2007; Gilchrist et at, 2001; Noterdaeme, Wriedt & Hoehne, 2010).

1.4 The Identification, Screening and Diagnosis of ASD

Developing and refining identification and assessment measures has been a significant research focus in recent years with research showing that inadequate identification of difficulties or conditions can lead to a lack of provision of adequate care (Brooks & Benson, 2013). Most research has focused on the identification of ASD in children, as early intervention can lead to improved outcomes (Rogers & Vismara, 2008; Norris & Lucavalier, 2010). However, ASD remains a lifelong disorder and as such, it is important to identify ASD in adults as awareness increases of the disorder, particularly in those who have been misdiagnosed in the past (Matson & Neal, 2009). Furthermore, prior to 1980, LD was seen as an inclusion criteria for the diagnosis of ASD and therefore, there are many adults with learning disabilities who may be currently undiagnosed.

Two categories of tools have developed in relation to ASD: screening and diagnostic tools. Diagnostic tools are aimed at assessing and diagnosing ASD in individuals whilst screening tools are used as a less costly and time-consuming method to identify symptoms related to ASD in order to help clinicians in decisions regarding whether to refer for a full diagnostic assessment (Brooks & Benson, 2013).

The complexity surrounding descriptions of ASD can lead to difficulties in identifying and diagnosing autism; this is particularly the case for adults with an LD with 80 per cent of GPs stating that they would require guidance to help them identify persons who may have ASD given the complexity (Allison, Auyeung & Baron-Cohen, 2012).

For example, diagnostic overshadowing (Reiss & Szyzko, 1983) can cause clinicians to assume symptoms are related to the LD rather than be attributable to the presence of another condition (such as ASD). Secondly, diagnostic substitution (King & Bearman, 2009) can lead to ASD diagnosed rather than LD. Additionally, the presence of neurological impairments can hamper diagnostic certainty (Matson & Shoemaker, 2009) and adults with

learning disabilities often have fragmented and unclear medical histories which makes it difficult to identify early symptoms or prevalence over the lifetime (Sappok et al, 2014). Finally, Balbomi, Coscarelli, Giunti and Schalock (2013) argue that those with an LD are less able to report their inner experiences, which can make describing symptoms difficult. All these factors would mean that not only do clinicians require skill and experience in noticing and interpreting symptoms of ASD in adults who have an LD, but that also tools need to be suitably specific and tailored towards the presentation of ASD in individuals with an LD. Front line clinicians, such as GPs are being called on more and more to refer for diagnostic assessment but partly due a lack of confidence in their own skills, screening tools have been suggested as a way of providing clinicians with a framework in helping them identify and make decisions regarding referrals for diagnostic assessments.

Currently the National Institute of Clinical Excellent (NICE) outlines the 'gold-standard' of procedures that should be followed when screening and diagnosing ASD in adults (NICE, 2012). NICE recommends clinicians use the Autism Quotient-10 ([AQ-10] Allison, Auyeung & Baron-Cohen, 2012) as a case identification tool for adults. However, they do not identify a suitable screening tool for adults with a moderate or severe LD and so recommend the clinician interviews a family member to identify traits, leaving the clinician to rely on their limited knowledge of LD and ASD in complex presentations. The diagnostic tools identified by NICE to use include the Autism Diagnostic Interview – Revised ([ADI-R] Lord, Rutter, & Le Couteur, 1994), the Autism Diagnostic Observation Schedule – Generic ([ADOS-G] Lord, Rutter, DiLavore, & Risi, 2002), the Autism Asperger Assessment ([AAA] Baron-Cohen, S,Wheelwright, Robinson & Woodbury-Smith 2005), the Asperger Syndrome (and high functioning autism) Diagnostic Interview ([ASDI] Gillberg, Rastam &Wentz, 2001) or the Ritvo Autism Asperger Diagnostic Scale – Revised ([RAADS-R], Ritvo et al., 2011). However, there are questions about the suitability of these tools for the purpose of

diagnosing ASD in adults who have an LD as they were not developed with this population in mind. This suggests there is a need for these tools to be reviewed with regards to their validity of being able to identify and diagnose ASD in adults who have learning disabilities rather than simply applying them to this population without their validity being investigated. Should these tools be found to be lacking, instruments would then need to be developed specifically for people with LD and ASD. The clinical implication of this would lead to more accurate, earlier and valid identification and diagnosis of ASD in adults with learning disabilities, which could lead to better access to support and improvements quality of life. Given that the majority of people with ASD have a learning disability, it seems appropriate that such diagnostic issues are worth perusing.

2. Literature Review

So far, this paper has introduced the issues of ASD in individuals with a learning disability and identified that such complexities can lead to difficulties with the case identification and diagnosis of ASD within this population. Without sufficient diagnostic methods, individuals may be unable to access appropriate interventions and needs could go unmet.

2.1 Aims

The aim of the current review is to bring together and critically evaluate all the available tools that claim to (1) screen, or (2) diagnose ASD symptoms in adults with learning disabilities. Although similar reviews have been written for tools used specifically with children, to the author's knowledge, this is the first review that critically examines screening and diagnostic tools developed for adults with an LD. The review is followed by a critique that will provide a discussion on the issues common to screening and diagnosing

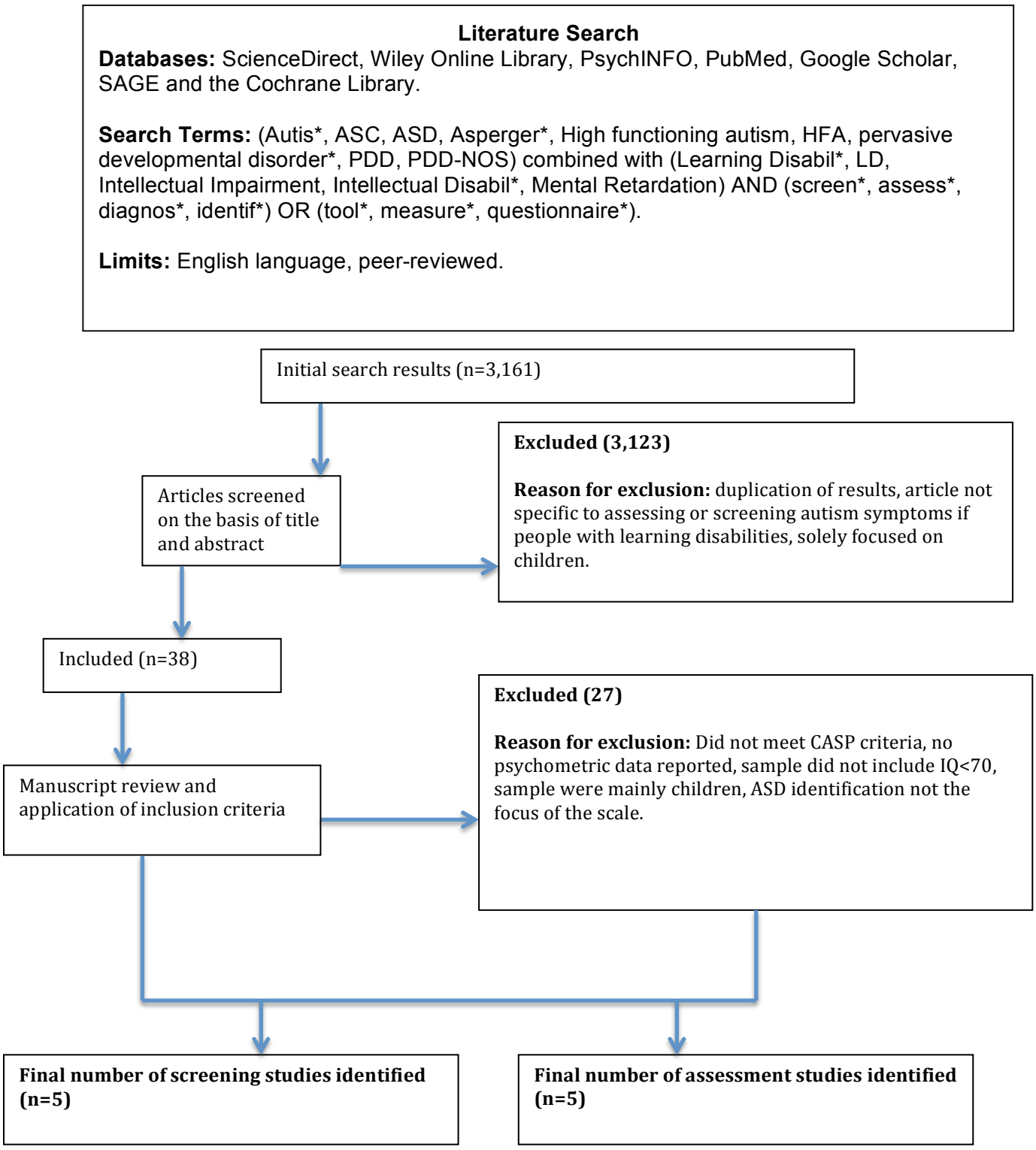
adults with a learning disability. Finally, implications for future research and clinical work are outlined.

2.2 Review Methodology

The literature review used the following databases to search for relevant papers: ScienceDirect, Wiley Online Library, PsychINFO, PubMed, Google Scholar, SAGE and the Cochrane Library. Additionally a hand-search was carried out based on the references of papers found from the initial search and where papers were not available via databases; authors were contacted for full texts where needed. A full description of the search strategy and search terms can be found in Figure 1.

The review only focuses on tools that have been developed for adults that have published findings on their diagnostic validity (i.e. sensitivity, specificity, etc.) and have be written up in at least one peer-reviewed journal in English. Additionally, scales that assess psychopathology in general (rather than ASD symptoms being the focus of the measure) were excluded. Also excluded were scales that were developed for the adolescent population (such as up to 22 years which technically covers adulthood). As well as the above criteria, the Critical Appraisal Skills Programme checklists were also held in mind (CASP, 2014) when including and critiquing papers. A brief overview of the aims and purpose of each paper is provided in Table 1; ten papers were identified.

Figure 1: Process of Selection of Reviewed Papers



Paper and date	***Aims***	***Tool***	***Sample***	***Methodology***	***CASP rating score***
Screening					
Berument, Rutter, Lord, Pickles and Bailey (1999)	To develop and test a screening questionnaire based on items in the Autism Diagnostic interview - Revised	SCQ	Total N=200; LD N=15	Case-control	7 out of 11
Brooks and Benson (2013)	To assess the validity of the SCQ in a sample of adults with intellectual disability.	SCQ	Total = 69; LD =69	Case-control	10 out of 11
Volkmar, Cicchetti and Dykens, (1988)	To evaluate the ASC on a group of ASD and non-ASD individuals.	ABC	Total=157; LD=143	Case-control	7 out of 11

Kraijer and de Bildt, (2005)	To assess the utility of the PDD-MRS as a screening instrument in identifying PDD in person with learning disability	PDD-MRS	Total=1,230; LD =1,230	Cohort	9 out of 11
Sappok, Graul, Bergmann, Dziobek, Bolte, Diefenbacher and Heinrich (2014)	To evaluate the DiBAS-R as a screening instrument for adults with intellectual disability and suspected ASD.	Di-BAS-R	Total=219; LD=219	Case-control	10 out of 11
Assessment					
Lord, Pickles, MacLennan et al, (1997)	To examine the effectiveness of the ADI-R in differentiating ASD	ADI-R	Total=330; LD = 107	Cohort	4 out of 11

	from LD and language impairment.				
Sappok et al,. (2013)	To evaluate the psychometric properties of the ADI-R and ADOS in a sample of adults with LD who were suspected of having ASD.	ADI-R & ADOS	Total=79; LD=79	Case-control	10 out of 11
Matson, Boisjoli, Gonzalez, Smith and Wilkins (2007)	To establish the cut-off scores for the ASD-DA for adults with LD and ASD or PDD-NOS	ASD-DA	Total=232; LD=232	Case-control	9 out of 11
Matson, Boisjoil and Smith (2008)	To investigate the convergent and discriminant validity of	ASD-DA	Total=307; LD=307	Cross sectional	NA*

	the ASD-DA.				
Belva, Matson, Hattier, Kozlowski and Bamburg (2012)	To determine the convergent validity of the ASD-DA.	ASD-DA	Total=278; LD=234	Case-control	7 out of 11

**No CASP checklist available for cross-sectional studies*

2.3 Screening Tools

Screening tools are used widely in the health service; in particular, screening tools can be used as additional information in deciding whether to refer an at-risk individual for full diagnostic assessment. In other words, screening tools provide a useful early step in the diagnostic pathway.

Flipek et al (1999) developed a set of recommendations that state what a good screening tool should consist of when being used to screen for ASD (Kraijer & de Bildt, 2005) (Table 2).

Table 2**.** *Characteristics of 'good' screening tools according to Filpek et al, (1999) and Kraijer and de Bildt (2005).*

Characteristic	***Description***
Client base	The tool should cover the full spectrum of IQ The normative sample should include persons of all aeitologies for learning disability. Additional disorders such as sensory deficits, motor disabilities, ADHD and psychoses should be represented in the proportion of the prevalence of these disorders should in he LD population The scale should be suitable for persons with a wide age-range
Purpose	The scale should be for screening only, although help in deciding about diagnostic assessments
Administration	The scale should be easy to administer and require no preparatory training

Scale content	The scale should cover current rather than detail histories
Scoring	Scoring should not require active cooperation of the individuals assessed
Ecological validity	The behavior being assessed should be readily observed at home and anywhere and not require special observations for it to be seen.

2.3.1 Social Communication Questionnaire ([SCQ] Berument, Rutter, Lord, Pickles & Bailey, 1999; Brooks & Benson, 2013).

The Social Communication Questionnaire (SCQ, originally titled 'ASQ' [Berument, Rutter, Lord, Pickles & Bailey, 1999]) is a 40-item screening questionnaire based on the Autism Diagnostic Interview ([ADI], Le Couteur et al., 1989) that examines areas such as social interaction, stereotypies, language and communication. It has two versions: the Lifetime, which assesses ASD symptoms present since early childhood, and the Current version, that measures present symptoms.

Berument and colleagues (1999) investigated the diagnostic and convergent validity, as well as factor structure with using the ADI-Revised (ADI-R) as a comparison. The sample consisted of 160 individuals. Of these, 83 had ASD diagnoses, 49 had atypical autism labels, 16 were classed as having Asperger syndrome as well at 7 with Fragile X Syndrome and 5 with Rett's Syndrome. Fifteen individuals in the sample had an LD, although no information is provided as to the specific IQ level making it difficult to say if the sample is representative of the full LD spectrum. Glasgoe (2005) states that the sensitivity of screening measures should be 80 per cent and specificity should be 70 to 80 per cent to guard against over-referrals (Brooks & Benson, 2013). However, where one might wish to prioritise sensitivity over specificity, an acceptable specificity can be lower. Alternatively, specificity can be

sacrificed for improved sensitivity where there one might be less concerned about the false positive rate (e.g. when initially screening).

Berument and colleagues found the SCQ to produce a sensitivity of 96 per cent and specificity of 67 per cent for differentiating ASD from learning disability, suggesting the measure is able to correctly identify those who have ASD to a good extent. Specificity was slightly lower than the Glasgoe (2005) criteria which could cause a higher rate of false positives, however, not considerably so. Moreover, specificity for this tool could actually be classed as very good considering sensitivity is so high. Diagnostic differentiation was found to be highly significant within all IQ categories but was clearest in the group with an IQ above 70. This suggests the measure is most suitable in individuals with an IQ in the borderline and above range.

The heterogeneity of the sample with regards to ASD diagnoses suggests that it may have good predictive power when used across the spectrum. However, the sample combined children and adults making it difficult to separate the validity for children and adults. Additionally, membership into the ASD diagnosis group was assessed using the ADI or ADI-R that had been administered several years previously. Although the ADI-R is described by NICE as being one of the tools helpful in making a diagnosis, it does not conform to the 'gold-standard' in which a clinical history and observations are also required.

This measure was further analysed by Brooks and Benson (2013) who carried out a study investigating the validity of the SCQ in adults with an LD whose developmental histories were unavailable or difficult to obtain. In this study, 69 adults (aged 19-40 years old) with a previous diagnosis of LD were administered the SCQ (Current), with the Aberrant Behaviour Checklist ([ABC-C;] Aman et al., 1995) and the Adaptive Behaviour Assessment System ([ABAS-II]; Harrison & Oakland, 2003) as tests of concurrent validity. Of these 69 adults, 21 had a diagnosis of ASD. ASD was diagnosed prior by psychologists or

psychiatrists experienced in the field (although the paper does not state specifically how this was done).

Results revealed that for a cut-off score of 12, sensitivity was 0.86 and specificity was 0.60 which was lower than the Berument (1999) study. It is worth noting that a lack of standardised assessment for ASD could cause the participant to be placed in the wrong group which could have falsely lowered the specificity of the SCQ in the sample (Brooks & Benson, 2013). Items on the communication domain displayed a poor internal consistency (alpha level of 0.48) which could be suggestive of the communication domain measuring more than one construct.

Other limitations, which the authors acknowledge, are that they were unable to match the participants for key characteristics that have been shown to impact performance on the SCQ, such as age, gender, or level of IQ (Charman et al., 2007). Furthermore, all participants were recruited from residential or day services, which may not be representative of all adults with ASD and LD as many are reported to live and work independently. Nevertheless the current study is the first to show that the SCQ Current could be useful as a carer-rated screening tool for at-risk adults when identifying ASD symptoms in those who have a learning disability.

2.3.2 Autism Behaviour Checklist ([ABC] Volkmar, Cicchetti, Dykens, 1988).

The Autism Behaviour Checklist ([ABC]; Krug, Arick & Almond, 1979) is an informant completed questionnaire and consists of questions concerning five areas of ability including sensory, relating, body/object use, language skills and as well as social and self-help domains. Some questions relate to historical information whilst other focus on current functioning with a cut-off score of 67 or higher indicating ASD. Volkmar, Cicchetti and Dykens (1998) investigated the ABC on 157 autistic and non-autistic but developmentally

impaired individuals. Diagnosis was established using DSM-III criteria by experienced clinicians. The autistic group consisted of 97 individuals with a mean IQ of 32.62. The non-autistic group consisted of 63 individuals with a mean IQ of 43.77, therefore having a significantly higher IQ (t =.16, p<.05). In addition to the ABC, a Vineland Adaptive Behaviour Scale ([VABS] Sparrow et al., 1984) was administered.

Results revealed that the measure could discriminate between the autistic and non-autistic group at statistical significance. Findings revealed sensitivity scores of 75 per cent and specificity of 81 per cent, however this analysis did not include the scores of the questionable cases. Furthermore, results reveal that false negatives were common amongst individuals in the higher IQ ranges, suggesting the measure is more sensitive in the lower IQ ranges (in opposition to the SCQ). Both inter-rater reliability and concurrent validity were fair however, the scale relies on historical information as well as current and this may be difficult for informants who do not have access to the case history. The authors conclude that the ABC cannot substitute careful clinical assessment and although may be sensitive to ASD symptomatology in adults in the profound range, it may be less helpful for those with higher IQs.

2.3.3 The Scale of Pervasive Developmental Disorder in Mentally Retarded Persons ([PDD-MRS] Kraijer & de Bildt, 2005).

The PDD-MRS is a screening instrument designed to identify PDD in adults with a learning disability. In the current study, Kraijer and de Bildt (2005) assessed whether the PDD-MRS may be a helpful screening tool to identify symptoms of ASD in people with a learning disability from the mild to profound ranges, aged between 2-55 years old. In this study, the researchers sought to test the PDD-MRS on a sample of 1,230 participants identified as having learning disabilities (although only 795 of these were adults). Reliability

was assessed by tests of internal consistency, inter-rater reliability and stability. Validity was established via discriminant validity (the ability to discriminate between the groups) and sensitivity and specificity. The scale also underwent factors analysis to assess that scale scores were independent of variables such as gender, IQ and age. Concurrent validity was not assessed as no appropriate analogous scales were found. Results revealed sensitivity values between 87 to 100 per cent depending on cut-off score with specificity between 84.6 and 95.5 per cent, which are within the appropriate ranges. However, subgroup analysis revealed poorer sensitivity and specificity. For example, findings revealed the PDD-MRS to be a less reliable measure for persons with a borderline learning disability suggesting it may be a more useful measure for individuals with IQs in the mild or lower range.

Other limitations of this instrument include the administration time. Although it is designed as a screening tool, it takes approximately 30 minutes to complete and must be administered by a specialist (e.g. psychiatrist). According to the criteria set out in Table 2, this could be seen as significant limitation. Even if the psychometric properties were found to be adequate for those in the borderline range, the above does raise questions as to the need for another tool when the SCQ shows good properties for this population and takes the same time to complete.

2.3.4 Diagnostic Behavioural Assessment for Autism Spectrum Disorder – Revised ([DiBAS-R] Sappok, Graul, Bergmann, Dziobek, Bolte, Diefenbacher & Heinrich, 2014).

The DiBAS-R is an informant based, 20-item questionnaire to screen for ASD symptoms in adults that is based on the International Classification of Disease criteria ([ICD-10], WHO, 1992) and DSM-5 criteria (APA, 2013). It is the first tool developed specifically based on the new classification of ASD. Sappok and colleagues (2014) investigated whether

the DiBAS-R could screen for ASD in adults with an LD on the item and scale levels.

The sample consisted of individuals recruited from an in- and out-patient psychiatry service in Germany (N=219). To receive intervention from this service, participants must have had a mental health or behavioural difficulty on admission, therefore all ASD assessment was administered following remission of the acute difficulty. Caregivers (parent or staff members) were given the DiBAS-R to complete over two occasions to assess inter-rater reliability. ASD diagnosis was assigned via multi-disciplinary team liaison based on all available information for the client, including standardised measures such as the SCQ, PDD-MRS and ADI-R. Level of LD was assessed by standardised IQ tests (although in some cases, level of IQ was assigned via psychiatrist clinical opinion based on adaptive functioning skills). Convergent validity was assessed via correlation with the SCQ, Autism Checklist in Adults with a Learning Disability ([ACL] (Sappok et al., 2013) and the PDD-MRS while divergent validity was assessed by correlational analysis with a non-ASD scale: the Modified Overt Aggression Scale (Knoedler, 1989).

Results revealed the DiBAS-R to have good sensitivity and specificity (81% for both) and good convergent validities when assessed against the other ASD scales. The inter-rater reliability was found to be appropriate (with inter-class coefficients of 0.88), although the confidence intervals were broad suggesting they should be interpreted with caution. Mann-Whitney *U* tests (as the data was at the ordinal level) indicated significant differences between participants with and without ASD in the DiBAS-R total score.

As well as good psychometric properties, the scale requires no preparatory training and is quick to administer suggesting the scale could be an efficient and reliable initial ASD screening of adults with LD. When compared to the PDD-MRS, the DiBAS-R does not display superior sensitivity and specificity values, however, the PDD-MRS requires an expert to complete it. One limitation however is that the sample consisted of individuals in the

middle of treatment for mental health difficulties. This means that many of the participants assessed would have been using psychotropic medications, which may have influenced behaviours being assessed by the DiBAS-R.

2.4 Summary of Screening Tools

Four tools were identified as possible screening measures for adults with an LD. The SCQ displays good sensitivity but the false positive rate was higher for this population. The SCQ displayed better properties for individuals in the borderline and above range. Although the DiBAS-R is less sensitive than the SCQ, it was specifically developed for an LD population and seems better with lower IQ scores (perhaps due to the selection of questions which specifically assess traits associated with the LD/ASD profile). Furthermore, IQ was estimated based on standardised assessments, which the other measures failed to establish. The PDD-MRS also shows appropriate properties but for individuals with lower IQ ranges, although has a longer administration time, making its use as a 'brief' screening measure less so.

2.5 Diagnostic Tools

The developments in the DSM and ICD criteria suggest the importance of developing appropriate measures that can be used to accurately diagnose ASD. Three assessment methods were identified in assessing ASD in adults who have a learning disability.

2.5.1 Autism Diagnostic Interview-Revised ([ADI-R] Lord, Pickles, MacLennan et al, 1997; Sappok et al., 2013b).

The ADI / ADI-Revised (ADI-R) is a diagnostic interview with carers that is widely used as part of the diagnostic process in assessing ASD. Symptoms are assessed over three

domains: RRBIs, language and communication and reciprocal social interaction (Lord et al, 1994). One study met criteria for examining the use of the ADI for adults with LDs and one for examining the ADI-R for diagnosing adults who have an LD with ASD.

Lord et al (1997) investigated the sensitivity and specificity of the ADI in differentiating ASD from LD and language difficulties in adults with different developmental levels via a cohort design. The sample consisted on 330 individuals separated into two groups: non-verbal (IQ ranging from 39 to 84) and verbal (IQ ranging from 80-144).

The ADI and ADI-R aim to provide a diagnostic algorithm for the ICD-10 definition of ASD (World Health Organisation [WHO], 1992) and DSM-IV (APA, 1993). Lord et al (1997) examined two different versions of the algorithm in their study: (a) one based on judgements on items describing current behaviours only, and (b) one based on judgements of whether abnormalities had ever occurred; thus suggesting this measure requires a clinical history which can sometimes be unavailable for some individuals with LD, particularly when carers rather than parents are being interviewed. Another limitation was that the number of individuals with ASD in each group was not representative of the normal population or of typical distributions of ASD versus non-ASD cases in clinic referrals and outcome appeared heavily dependent on the assessor's clinical judgement of the carers' descriptions.

The authors found that in general, items showed lower specificities for lower functioning individuals (indicating more risk for false positives) and lower sensitivity for high-functioning individuals (suggesting the measure may not be sufficiently sensitive for individuals at the higher end of the IQ range.

Sappok et al (2013b) investigated further by administering the ADI-R to adults with an LD who were suspected to have ASD. Participants consisted of 79 adults above 18 years old with a learning disability. Diagnosis was determined by a multidisciplinary team liaison where the study took place; ICD-10 criteria was used to identify 55 of the participants as

having ASD. The remaining participants were not diagnosed with ASD but did receive diagnoses such as Attention Deficit Hyperactivity Disorder (ADHD), schizophrenia, obsessive-compulsive disorder (OCD), attachment disorders or sensory deficits. Two participants who had originally been diagnosed with ASD prior to the study were re-diagnosed with schizophrenia and anxiety disorder. Each participant was administered the ADI-R by a clinician blind to the final diagnoses. As well as the ADI-R, the SCQ and PDD-MRS was administered as a test of concurrent validity.

Results revealed good sensitivity (87.5%) and specificity (80%), which are similar to the sensitivity and specificity values found in other studies assessing children with learning disabilities (De Bildt et al., 2004). These results suggest promise in using the ADI-R in adults with an LD who are suspected of having ASD whenever historical information is available.

However, worth noting is that this study did have a small sample size compared to other studies (De Bildt et al., 2004: N=184). Additionally, participants' IQ was not assessed via standardised assessment making it difficult to draw conclusions regarding LD subtypes in relation to the measure. Furthermore, one of the authors of this study receives royalties for the German version of the ADI-R, leaving results open to bias, although this is acknowledged within the paper.

2.5.2 Autism Spectrum Disorders – Diagnosis for Adults (]ASD-DA] Matson, Boisjoli, Gonzalez, Smith & Wilkins, 2007; Matson, Boisjoil & Smith, 2008; Belva, Matson, Hattier, Kozlowski & Bamburg, 2012).

The Autism Spectrum Disorders – Diagnosis for Adults (ASD-DA) is an assessment used to measure ASD symptomatology in adults specifically with learning disabilities. The utility of this measure has been assessed over three studies from 2007 to 2012.

The fist study carried out in 2007 by Matson and colleagues (2007) aimed to assess

the usefulness of the ASD-DA in discriminating between those who have ASD and those who do not in adults with an LD. The authors also aimed to find out if the ASD-DA could discriminate between ASD and PDD-NOS. Participants consisted of 232 individuals aged 20 to 80 years old with a range of LD from profound to mild. In this case-control study, the ASD-DA was administered with participants having a prior diagnosis using the DSM-IV / ICD-10 as the reference standard. Doctoral level psychology students carried out the assessment with care workers who had been supporting the participants for at least 6 months.

Matson et al (2007) reported that the ASD-DA was able to discriminate those with a diagnosis of ASD in adults with an LD with good sensitivity (0.86) and specificity (0.62) when using a cut-off score of 19. However, when differentiating between the ASD groups (ASD and PDD-NOS), poorer sensitivity (0.94 for Factor I; 0.56 for Factor III) and specificity (0.31 for Factor I and 0.57 for Factor III) was found. Although, given that the new DSM criteria does not discriminate between ASD and PDD-NOS, it is possible that this may not represent a limitation when using the ADOS as a diagnostic tool in current practice.

Further psychometric properties were investigated in the 2008 study (Matson, Wilkins, Boisjoli & Smith, 2008). A variation of the multitrait-multimethod approach (Campbell & Fiske, 1959) was used as a practical methodology to analyse the convergent and discriminant validity of the measure. In this cross sectional study, the ASD-DA was tested on 307 participants ranging from 16 to 88 years old. The analogous measures used to assess construct validity included the Diagnostic assessment Disorders of the Severely Handicapped-II ([DASH-II], Matson, 1995a) questionnaire, the Matson Evaluation of Social Skills for Individuals with Severe Retardation ([MESSIER] Matson, 1995b) and a composite checklist of ASD symptoms from the DSM-IV-TR (APA, 2000) and ICD-10 (WHO, 1992). In addition, the Socialisation domain of the Vineland Adaptive Behaviour Scales ([VABS] Sparrow et al., 1984) was administered. Correlations were expected between the ASD-DA

and DSM-IV-TR / ICD-10,criterias, scores on the MESSIER and VABS (representing tests of convergent validity) whereas the authors expected the DASH-II to have no correlation with the ASD-DA (representing tests of divergent validity).

Results reveal that there were highly significant negative correlations between the ASD-DA and MESSIER and the ASD-DA and Socialisation domain of the VABS. However, a less strong relationships with the DSM-IV-TR / ICD-10 was found, suggesting that the ASD-DA may converge less well with the DSM-IV-TR / ICD-10 criterias. A non-significant relationship was found between the ASD-DA and the DASH-II indicating good discriminant validity.

One limitation of this study was that the sample consisted of individuals from a developmental centre, the majority of whom were found to have needs in the severe range (Matson et al, 2007). This means that one can only say the ASD-DA shows good construct validity for individuals in the severe range of LD. Further investigation is needed with regards to the validity of the measure for those in the moderate or mild range. Furthermore, the information collected was given from staff who had only been working with the participants from six months up to 10 years and as such would mean wide variations in how symptoms get reported (perhaps due to desensitisation or experience over time).

The final paper included that examines the ASD-DA also studied convergent validity (Belva, Matson, Hattier, Mozlowski, Bamburg, 2012). In this study, 278 adults aged 16-88 years old were assessed using the ASD-DA and the PDD/Autism subscale of the DASH-II (as this measures ASD traits in those with a learning disability). Again, the participants were all in the severe or profound range of LD and are thus not representative of the full IQ LD range.

Results reveal that the PDD/Autism subscale on the DASH-II was significantly positively correlated with the ASD-DA total score ($p<.001$, $r=.28$) which supports the 2008

study of a moderately good convergent validity with a medium effect size.

The large sample size, along with the quick administration and showing good results for individuals in the severe and profound ranges makes the ASD-DA an appealing instrument when assessing ASD symptomatology in adults with an LD.

2.5.3 Autism Diagnostic Observation Schedule ([ADOS] Sappok et al., 2013).

The ADOS is a semi-structured, standardised observational assessment tool consisting of four modules to assess social and communication abilities in those suspected of having ASD (Lord et al, 1989; 2000). The ADOS has two different cut-offs to indicate ASD (mild variant or severe variant) in order to optimise sensitivity and specificity. Authors recommend it not be used as a stand-alone diagnostic tool as it does not elicit any information about the developmental history (and so is often used in conjunction with the ADI-R). One study reports using the ADOS with adults with a learning disability.

Sappok et al. (2013) administered the ADOS to adults with an LD to assess its reliability and validity in this population. Elements of the administration procedure for the ADOS were changed, such as the free play tasks, to make them more age appropriate for adults.

Results revealed that the ASD group scored higher means compared to the non-ASD group; this finding was not significant (perhaps due uneven sample sizes in each group). An ANOVA did not reveal any significant group differences within the LD groups and between the ADOS total scores. Internal consistency (calculated via Cronbach's alpha) was greater than 0.8, suggesting good consistency. Sensitivity and specificity was found to be 85 and 60 per cent respectively for the severe variant and 100 and 45 per cent for the mild variant. The correlation between ADOS and ADI-R was low and non-significant.

These results suggest that the ADOS may be over inclusive (as demonstrated by high

sensitivity but low specificity values) for this population. Furthermore, it appears that some of the ADOS ratings could not be completed due to the characteristics of the participants, suggesting the ADOS might not be wholly suitable without significant adaptations that may reduce the specificity and feasibility further. The authors state that in order to improve the applicability of the ADOS in individuals with an LD (particularly severe LD), age-appropriate materials should be chosen to evaluate interactive skills better. Although the administration procedures were stepped away from by using this more naturalistic design which was found to reduce the reliability to the ADOS, in reality this design is more likely to reflect what clinicians find themselves doing on a day to day basis when faced with clients that may not perfectly match the profile of those whom were used as the norming sample of the ADOS. In this sense, the above procedures represent perhaps a more ecologically valid picture of using the ADOS.

2.5.4 Summary of diagnostic tools.

Three assessment tools fit criteria for assessing ASD in adults with an LD. Results suggest the ADI /ADI-R may not be sensitive enough for individuals who have relatively higher IQ ranges and is dependent on obtaining good data from the informant. All studies had problems with the samples in that they were either too small (i.e. the ADOS), not representative of the full LD IQ range (i.e. ASD-DA/ADI ADI-R) or had uneven sample sizes (i.e. the ADI / ADI-R). The ASD-DA showed good properties but was unable to differentiate between the ASD and PDD-NOS groups. Similar to the screening tools, all measures compromised specificity, indicating the measures may be more at risk of producing false-positives when adhering to the specified cut-offs.

2.6 Summary of Screening and Diagnostic Tools

Results suggest that thus far, both screening and diagnostic tools identified have issues with assessing ASD symptoms in adults with an LD. A wider view of issues common to all is discussed below.

3 Critique

3.1 Methodological Issues Common To All

Methodological issues have been discussed above, however, it is worth noting that all studies showed difficulties in sampling. Most studies recruited adults who were already accessing services (day centres, out- or in-patient units, residential homes etc). This means that samples are biased towards those deemed severe enough to need this type of support. Many adults with mild or borderline learning disabilities do not access these types of services and may in fact go unnoticed amongst services but may well be experiencing symptoms of ASD (Krahn, Hammond & Turner, 2006). Therefore, this particular profile could be missing from the extant evidence base.

Additionally, many of the groups of participants who were recruited were not matched. Furthermore, IQ was not always assessed via the same methods (standardised IQ measures, measures of adaptive functioning or clinical opinion) making it difficult to compare the findings across studies. Even in the cases where participants were assigned an LD range via the use of standardised assessment, it may still not be possible to say that those in a particular LD group are all the same, i.e. are appropriately matched. This is because IQ profiles tend to be uneven in ASD profiles. Jarrold and Brock (2004) found that individuals with ASD do not have a flat profile, but rather show peaks and troughs of performance across the different subtests.

An additional challenge is that many of the tools were developed with the DSM-IV or ICD-10 criteria in mind. These diagnostic classifications were established from literature that

was based on very small and biased samples (e.g. mostly westernised males). Therefore, the assessment tools that base their criteria on these classifications are also basing their criteria on small, biased samples. This leads to questions about the DSM and ICD-10 classifications as being valid constructs in themselves; particularly as such constructs are susceptible to prevailing Zeitgeists (Jablensky, 1999).

3.2 A One-Size Fits All Approach

Results reveal that many of the measures performed better or were more appropriate for individuals at a certain end of the IQ range. For example, the SCQ proved to be more sensitive to those in the borderline range, where as the DiBAS-R seemed to have better reliability for individuals within the severe range. One the one hand a tool that can be used on the full spectrum of LD may be useful and easier to administer (Filpek et al., 1999) but perhaps the above findings suggest that a 'one-size fits all approach' may not be appropriate for the case identification and diagnosis of ASD in those who have a learning disability. Findings show that the ASD profile of symptoms noticed in individuals with a severe LD is different from those with borderline or mild levels of LD. Therefore, perhaps clinicians need to decide what tools to use on a case-by-case basis, taking into account the level of LD, rather than using one tool for the full LD range.

3.3 Paucity of the Evidence Base and Clinical Versus Research Lenses

One of the striking features of the above review is the amount of studies that were excluded from the initial list of tools identified. Although there have been many tools developed (particularly diagnostic measures), the majority of these have not been validated or been evaluated for use with adults with IQs below 70 (*see appendix 1 for a full list of excluded measures with reasons*).

This paucity of research in this area leads clinicians to have few options when considering tools to help in making decisions regarding referrals or diagnoses. This finding seems odd given that prevalence rates show that the majority of individuals with ASD also have an LD (LaMaifa, Lassi, Bertelli, Salvini & Placidi, 2004). Furthermore, the amount of studies that had to be excluded from this review due to them not meeting the criteria of their samples consisting of participants with a diagnosis of LD is striking. This suggests that there is a mismatch between measures that are being developed and investigated in research, versus the clinical reality of what services are currently experiencing and need in a measure. It will be interesting to see how this dichotomy changes with the introduction of the new DSM criteria that does not separate out high functioning autism.

There could be a number of explanations as to the reasons for this disparity. One explanation is that IQ is possibly the biggest construct, other than ASD, that affects the presentation of ASD symptoms. The heterogeneity inherent in IQ makes matching groups difficult (Jarrold & Brock, 2004). One could hypothesise that researchers therefore find it easier to exclude LD participants from their samples to make findings clearer.

This mismatch is also played out in the guidelines themselves. For example, the recent revised NICE guidelines for the identification, diagnosis and intervention of autism in adults (NICE, 2012) make very little mention of comorbid learning disability. In fact, they recommend the use of a self-report tool called the AQ-10 (Allison, Auyeung & Baron-Cohen, 2012) as a screening tool for those with a borderline or mild LD; a measure that has been solely used and validated on individuals with an IQ above 70 consisting of university students.

The NICE (2012) guidelines were developed by a panel of experts in ASD, one of who is one of the co-authors of the AQ-10 (Allison, Auyeung & Baron-Cohen, 2012). One view of a difficulty inherent in the ASD literature base is that those who have produced the

majority of articles may have a stake in developing the intervention of choice. This could lead to the allegiance effect where by the most effect treatment (or in this case, assessment tools) are found to be the ones to which the researcher holds a theoretical allegiance (Lambert 1999).

4 Implications and Areas for Future Research

Guided by the above findings, there are some possible areas in which future work could be focused with regards to identifying and assessing ASD in adults who have a learning disability.

Firstly, the paucity of research shows that there is more input needed into this field, specifically, studies would benefit from being replicated. A possible research question for the future would be whether screening and diagnostic tools for adults with learning disabilities would be more valid and reliable if they were specific to level of LD. In other words, is a 'one-size fits all' or LD specific measure more useful?

Secondly it would be helpful to address the differences in how the ASD/LD profile is perceived and worked with between research, clinical work and national guidelines milieus. Michel Foucault described the dangers of power being the determinant of shaping the knowledge and narratives that are held as 'truths' (Foucault, 1991; Rabinow, 1991). By being aware of issues such as the allegiance effect and questioning the validity of constructs such as the ICD-10 and DSM criterias, we can allow for a richer understanding of ASD. Researchers and clinicians alike will have to work hard to find ways of thickening obscured narratives, perhaps by re-examining the idea of an 'expert' when drawing up guidelines. The inclusion of more clinicians or service-users could provide a helpful voice in moving forward.

5 Conclusions

The current review aimed to bring together and critically evaluate the available screening and diagnostic tools used to identify and diagnose ASD in adults with learning disabilities in the hope of making recommendations as to the best tools to use for this population. To the author's knowledge, this has not been done before.

With regards to screening tools, four measures were identified as being possibilities: the SCQ (Rutter, Lord, Pickles & Bailey, 1999) PDD-MRS (Kraijer & de Bildt, 2005) and DiBAS-R (Sappok et al., 2014). The SCQ could be considered for individuals with learning disabilities in the mild or borderline range, whereas the PDD-MRS should be considered for the moderate to severe range. The PDD-MRS requires more administration time and expertise and so is reflective of the inherent difficulty in assessing and screening co-occurring ASD/LD, particularly in the more severe ranges. The DiBAS-R shows promising psychometric properties and was specifically developed for the LD population in mind. However, all measurements require replication and further validation for this population before conclusions can be drawn.

For diagnostic tools, only three tools met criteria to be reviewed (ADI/ADI-R, Lord, Rutter, & Le Couteur, 1994), [ADOS] Lord, Rutter, DiLavore, & Risi, 2002, [ASD-DA] Matson, Boisjoli, Gonzalez, Smith & Wilkins, 2007). The ADI-R and ADOS are considered the 'gold standard' in adults with IQs above 70; however, findings reveal that they may be less useful for adults with a learning disability. The ADI-R may not be sensitive enough for adults at the higher end of the LD range and the ASD-DA had difficulties in differentiating ASD from PDD-NOS. Specificity was an issue for many of the assessment and screening measures alike with a higher likelihood of false positive rates than for adults without an LD. All studies had difficulties with obtaining representative, large and matched samples, leading to difficulties with generalisability.

The findings of the above review call into question the utility of a 'one-size fits all' approach to screening and diagnostic measures and instead alludes to the potential benefit of having measures that are specific to different presentations of learning disability (i.e. a measure specifically for those in the mild range and a measure specifically for those in the profound range). This is consistent with the literature, which suggests ASD symptoms are both quantitatively, and qualitatively different across the LD ranges (Matson & Shoemaker, 2009).

Overall, the paucity of research in this area suggests the need for further studies in investigating appropriate case identification and diagnostic methods for adults with learning disabilities. This under-researched area will be aided by ensuring that those involved in researching autism hold in mind the importance of including those with learning disabilities in their samples, rather than the presence of learning disability being an automatic exclusion criteria.

Finally, the review suggests that the recommendations suggested in the NICE (2012) guidelines for the case identification and diagnosis of ASD in adults may have overlooked the complexity of ASD in those with learning disabilities.

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Running Head: USING THE AQ-10: PILOT ANALYSIS OF AN ADAPTED AQ-10

Section B: Using the AQ-10 with Adults who have a Borderline or Mild Learning Disability: Pilot Analysis of an Adapted AQ-10

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Abstract

There is a need for appropriate screening tools for the case identification of autism spectrum disorder (ASD) in those with learning disabilities (LD) given the co-occurrence of the two conditions. The AQ-10 is the screening tool recommended by NICE (2012) for the identification of ASD in adults with a borderline or mild learning disability. However, the AQ-10 was not developed with this population in mind. A mixed-methods approach was used to investigate the utility of the AQ-10 in its original form as a case identification tool. The AQ-10 was then redesigned and piloted. Qualitative results revealed individuals found the AQ-10 too inaccessible in its current format. Following revision, the diagnostic validity of the revised measure (AQ-10-R) showed good sensitivity (0.85) and specificity (0.77), whereas the diagnostic validity of the original AQ-10 was poor. The internal consistency for the AQ-10-R was 0.67 and 0.30 for the AQ-10. These findings indicate that formatting and administration changes may be needed to the AQ-10 before clinicians consider using it when helping to make decisions regarding referral for diagnostic assessment in those with borderline or mild learning disabilities.

***Keywords*: Learning Disability, Autism Spectrum Disorder, Intellectual impairment, Screening, Case identification, AQ-10.**

Section B: Using the AQ-10 with Adults who have a Borderline or Mild Learning Disability: Pilot Analysis of an Adapted AQ-10

1. Introduction

Autism Spectrum Disorder (ASD) is a term used to describe a set of difficulties with social communication, social interaction and restrictive and repetitive behaviours (RRBIs) (Lai, Lombardo & Baron-Cohen, 2014). It is one of the most diagnosed neurodevelopmental conditions worldwide with prevalence estimates between one and two per cent for adults (Brugha, MacManus, Bankart, et al., 2011). Matson and Shoemaker (2009) state that those with ASD are also likely to have a learning disability (LD). Learning disability is a term used to describe those with an impairment in adaptive functioning (e.g. daily living skills) and a full scale intelligence quotient (IQ) below 70 (British Psychological Society [BPS], 2000). Prevalence rates of comorbid LD and ASD range from 40% of persons with LD having ASD and 70% of persons with ASD having LD suggesting high co-occurrence of the two conditions (LaMalfa, Lassi, Bertelli, salvini & Placidi, 2004).

The identification and assessment of ASD has been a significant research focus in recent years (Brooks & Benson, 2013). Much work has been given to the identification of ASD in children. However, as ASD occurs across the lifespan, there is a need for appropriate tools to identify ASD in adults. Furthermore, before 1980, the presence of a LD was an exclusion criteria for an ASD diagnosis and therefore there may be many adults now presenting to services who were previously undiagnosed. According to the National Institute for Clinical Excellence (NICE), inadequate identification leads to a lack of adequate provision of care (NICE, 2012). However, case identification is limited by the availably of well-validated tools (for a review, see section A). Punshon, Skirrow and Murphy (2009) state that the level of training and knowledge of ASD is limited

amongst front line professionals. This, combined with the challenges known in identifying ASD, such as diagnostic overshadowing (Reiss & Szyzko, 1983), diagnostic substitution (King & Bearman, 2009), unclear medical histories (Sappok et al., 2014), difficulties with self-reporting and describing symptoms (Balbomi, Coscarrelli, Giunti & Schalock, 2013) presents significant challenges and skill needed on the part of the practitioner for case identification. In fact, 80 per cent of GPs state that they would require guidance to identify persons who may have ASD given the above complexity (Allison, Auyeung & Baron-Cohen, 2012).

NICE (2012) state that case identification tools (or 'screening instruments') should be age-appropriate, severity-appropriate, brief, and not themselves be diagnostic. Filpek and colleagues (1999) also set out some guidelines of what a screening tool in relation to ASD and LD should look like. They recommended that the measure should be inclusive of all IQ ranges and all aetiologies for learning disability and should be easy to administer, where behaviour being assessed should be readily observed and not require special observation.

NICE guidelines (2012) provide advice on screening tools that may be useful for clinicians in identifying ASD in adults. They recommend the use of the Autism Quoteint-10 ([AQ-10], Allison, Auyeung & Baron-Cohen, 2012) for adults who have a borderline or mild LD or for those with an IQ above 70. The AQ-10 is a self-report, 10-item measure that individuals complete by filling in the extent to which they agree or disagree with ten statements presented (Appendix 2). The guidelines state that the questionnaire should be read out loud if the individual has reading difficulties. A score above six would suggest presence of ASD symptomatology and warrant a referral for diagnostic

assessment. For those with a moderate or severe LD, it is recommended that the screening process involves clinicians undertaking a brief assessment asking about the triad of impairments, relying on the clinicians' knowledge and skill.

The AQ-10 was developed from the AQ (Baron-Cohen, Wheelwright, Skinner, Martin & Clubley, 2001). Allison, Auyeung and Baron-Cohen (2012) identified the most discriminating items across five subscales that were derived from theory of the 'triad of impairment' (Rutter, 1978; Wing & Gould, 1979). Specifically, the items they chose focused on domains of ability including attention to detail, attention switching, communication, imagination and social skills.

As yet, only one study has investigated the AQ-10 in terms of its psychometric properties and reported good findings (Allison, Auyeung & Baron-Cohen, 2012). Sensitivity (the ability of the measure to detect true positives) and specificity (the ability of the measure to detect true negatives) were found to be 0.88 and 0.91 respectively with internal consistency being estimated at an alpha level of 0.85 and discriminant validity ranges from 0.37 to 0.62. However, the sample consisted solely of adults with IQ's above 70, leaving questions as to how the measure would perform for adults in the borderline or mild range of impairment.

As well as the AQ-10 not being validated or yet tested on individuals with borderline or mild learning disabilities, there are other issues that could make this measure difficult to use with this population. For example, methodological issues are widely documented in the literature when using self-report measures with individuals with learning disabilities (see Finlay & Lyons, 2001 for a review). This suggests that more attention needs to be paid to establishing the validity of using the AQ-10 on this

population, rather than suggesting that reading the measure out loud is an adequate adaptation to overcome such difficulties.

As described above, the identification of ASD in adults is complex with difficulties in needing significant expertise to understand and interpret symptoms. Furthermore, a paucity of appropriate screening measures makes case identification even more challenging. Recommendations have been made to use the AQ-10 as a brief screening tool but this might not be appropriate for the majority of adults with ASD as many of these persons also have a learning disability. The AQ-10 was not developed for individuals with IQs below 70 in mind and therefore this, taken together with findings that suggest self-report tools need significant methodological adjustment if being used on individuals with learning disabilities, suggests that one may presume that the AQ-10 might not be useful or valid for adults with ASD in its current form.

The purpose of this study was to explore whether the existing AQ-10 is adequate for the need of screening adults with a borderline or mild learning disability who may also have ASD. Then, to redesign the measure and discover whether adaptations made to the AQ-10 can maintain, or improve, its psychometric properties in detecting the presence of ASD symptomatology in adults with a diagnosis of borderline or mild learning disability.

2. Aims and Hypotheses

The project was carried out in two stages. Stage one (consultation phase) addressed the following research questions:

1. How do adults with a borderline or mild learning disability experience using the AQ-10?
2. Do individuals with a borderline or mild learning disability understand the AQ-10?
3. Does the measure need revising, and if so, in what ways?

Stage two (measure redesign and initial pilot) aimed to redesign the measure using the recommended steps of scale development (De Vellis, 1991; Oppenheim, 1996; Rattray & Jones, 2005) and then collect some early data to investigate the:

4. Usefulness of the adapted and un-adapted AQ-10 in discriminating between adults with LD with and without ASD.
5. Sensitivity and specificity of the adapted and un-adapted AQ-10 for adults with a borderline or mild LD.
6. Internal consistency of the adapted and un-adapted AQ-10 for adults with a borderline or mild learning disability.

3. Phase 1 Methods

3.1 Design

A focus group was used for the consultation phase of the study. Semi-structured questions were used with responses being analysed using thematic analysis. (Braun &

Clarke, 2006). A qualitative approach was chosen to allow for in-depth, richer exploration of the research questions (Boyatzis, 1998).

3.2 Participants

Participants were recruited from a learning disability service-user group whose primary aim is to provide consultation on the accessibility of National Health Service (NHS) documents. Participants were eligible to participate if they had a borderline or mild learning disability and were able to give informed consent.

Six participants agreed to take part in the focus group. The participants ranged in age from 28 years, six months to 52 years, two months (mean age 37 years, two months, *S*D = 9.8). Four of the participants were female (2 males). All participants had a mild learning disability and 50% had a mental health or physical health disability. One participant had ASD.

3.3 Measures and Materials

The semi-structured interview questions were constructed by researching relevant literature and liaison with experts in the field (Appendix 19). The questions were open-ended to allow for depth and elaboration.

3.4 Ethical Considerations

Ethical approval was sought and obtained from a NHS Research Ethics Committee (REC) and Research and Development department (Appendix 3 & 4). In addition, the British Psychological Society (BPS) Code of Ethics and Conduct was

conformed to during the study (BPS, 2009). Confidentiality was maintained by using anonymous ID numbers. All data was stored in a locked cabinet and data were coded and kept on password protected USBs.

In order to obtain informed consent, the information sheet (Appendix 6) was given and read out loud to the participant. The researcher then answered follow up questions and checked understanding by asking them questions about the procedure and their rights as a participant. If it was thought that they had understood the procedure and still wanted to participate, written informed consent was obtained. Where participants had difficulties with reading or writing, the experimenter helped them fill in the consent form.

3.5 Procedure

Focus group members were given the AQ-10 and spent some time using it by themselves before discussing it in the wider focus group. Participants were asked questions about the AQ-10 by the author of this project. Also in attendance were the organisers of the service-user group to provide a familiar face for participants and extra help in facilitating the group if needed. Participants were given written and verbal information prior to attending and again on the day. The focus group was recorded on a dictaphone and all data was kept in line with the Data Protection Act (Great Britain Parliament, 1998).

3.6 Data Analysis

Braun and Clarke's (2006) method of thematic analysis was used. Data was recorded, transcribed, coded and analysed in order to report and understand themes

within the data. In some cases, the same code was ascribed to more than one theme. An inductive, data-driven approach was used to allow for themes to emerge, rather than being driven too heavily by pre-existing ideas or the researcher's own ideas (Frith & Gleeson, 2004).

After coding the data, a thematic map was generated. The external supervisor, an expert in ASD measurement, was given the transcripts to read and check the thematic map for quality assurance. The themes were checked to make sure they were an 'accurate' representation of the data set as a whole. Discrepancies were discussed and final themes generated following checking. The author read the transcripts a final time to check for an additional data to fit the themes identified.

4. Phase 1 Results

4.1 Thematic analysis.

Outlined below are the main findings of the thematic analysis according to each of the project aims (see Appendix 10 for the code book and Appendix 15 for a sample of the transcript). A thematic analysis of the focus group resulted in two master themes and nine subthemes, outlined in Table 1, which will be explained further with examples below.

Table 1. Thematic analysis summary

Master theme	**Subtheme**	**Who commented**
Understanding of the measure	Readability	P3; P1; P8
Participants describe their	Formatting / layout	P1; P2; P3; P7; P8
understanding of the AQ-10	Literal interpretations	P1; P2; P8
	Subjectivity	P1; P3; P4
Approach to the task	Guessing	P1; P5; P8
Participants describe how they	Using visual cues	P1; P5; P8
experienced and approached using	Using real life examples	P1; P8
the AQ-10	Emotional experiences	P1; P2
	Dependency vs. autonomy	P1; P2; P8; P7

Understanding of the measure.

Readability.

Participants appeared unconfident in being able to understand the questions. They found the reading ability required to understand the questions too demanding and were unsure whether the answers they gave reflected what the questions were asking of them. Participants described some words being too long, e.g. words like “concentrate”, “interruption” and “intention” and also spoke of the sentences themselves being too lengthy.

Formatting / layout.

Participants described having difficulty with understanding various aspects of the questionnaire format and design. Some described the Likert Scale as being confusing, with too many options to choose from. Others suggested reducing the options to just a

'Yes/No' response. Some felt that they would also want a 'maybe' or 'don't know' option. One participant had an idea of using cartoon faces (smiley, sad) to make the Likert scale easier to understand.

Participants described getting distracted by the scoring information for clinicians at the bottom of the questionnaire. One participant described not wanting information that is not for them on the page and another suggested that some information regarding start and finish places might be useful.

One participant commented that they wanted space to write their name on the form so the questionnaire would not get "muddled up" with someone else's.

Literal interpretations.

Some participants made literal understandings of the questions. For example, when asked about their understanding of the phrase "I usually concentrate on the whole picture", participants described this meaning an actual picture rather than the metaphorical understanding of the phrase. Some participants also appeared to have difficulties with generalisability, for example, when asked about their understanding of question eight which asks about obsessions / RRBIs ("I like to collect information about categories of things, e.g. types of car, types of bird, types of train, types of plant etc), one participant commented that this question was asking if they liked birds.

Subjectivity.

One question asks the participant to make judgements regarding how quickly they can get back on task after being distracted. It appeared that participants had different ideas about what "quickly" meant to them, suggesting participants are making subjective decisions when using the questionnaire.

The AQ-10 is structured so that participants have to agree or disagree with the statements presented (e.g. “I often notice small sounds when others do not”). One participant commented that he did not understand who “I” was, wondering if it referred to him or the person who had written the questionnaire. This suggests that more direct questions, such as “*Do you* notice small sounds”, might be easier to understand than first person agree/ disagree statements.

Approach to the task.

Guessing.

Participants described that in the absence of not understanding the questions; they would guess their response. Absent from the discussion were participants stating that they would ask for help or clarification if they did not understand. This implies that it would be difficult to know if the answer supplied was an accurate representation of the respondent’s view.

Visual cues.

Some participants placed importance on visual information to aid understanding and clarity. All participants spoke unanimously of their desire for coloured pictures to be used on the measure. They stated that they would prefer easy to read symbols as they are already familiar with these rather than photos and that colour would help important bits of information stand out.

Real life examples.

When the group discussed each question’s meaning, they linked them to real life examples to clarify understanding. For example, when being asked about multi-tasking, a

participant used an example of housework to gauge whether he had understood the question. It appeared understanding increased when participants could link it to something they had real life knowledge of or more contextual information for, for example, being able to understand a question asking about facial expressions due to having attended a course on body language.

Emotional experiences.

Participants described wanting to fill in the questionnaire and being willing to engage with the measure. One participant appeared to put in a lot of effort by going back and trying to re-read the questions in the hope that she would understand them the next time and therefore it appeared using the questionnaire felt like an effortful process. Participants described that the measure evoked some emotions when they were using it. These tended to be more negative emotions such as anxiety, fear and worry.

Dependency vs. autonomy.

Participants conveyed that they would need support in order to help them fill in the questionnaire, suggesting that the experience of using this questionnaire would not be an autonomous one. It appears that the self-report nature of the questionnaire becomes obscured when using it with people with a mild learning disability. When asked if they would still need support if changes had been made like adding pictures, some commented that they would still need help; others were less sure. This ambiguity leads to questions as to whether the questionnaire is best administered as a semi-structured interview or self-report tool; perhaps suggesting decisions need to be made on a case-by-case basis.

4.2 Summary of Results

The aims for phase one of the study was to understand and conceptualise how adults with a borderline or mild learning disability experience using the AQ-10, in particular, discovering whether the AQ-10 can be understood by them or, whether it may benefit from a revision or adaptation.

When analysing the results in terms of these initial research questions posed, it appears that most adults within the focus group had difficulties in understanding the AQ-10 in its original format. The difficulties that emerged centred on themes of readability, difficulty in understanding the layout and scaling, difficulties in understanding metaphor and the AQ-10's reliance on abstract information.

The results suggest that people with a borderline or mild learning disability experience using the AQ-10 as a challenging process, with negative emotions associated with taking the measure, in particular fear and anxiety were generally evoked. This suggests that the measure could indeed benefit from a revision, particularly addressing the problematic areas identified above. It is this task that is the focus of phase two of this study, and is described in the next section.

5. Phase 2 Methods

5.1 Design

In phase two, the design followed the recommended steps of scale development (Oppenheim, 1996; DeVellis, 1991; Rattray & Jones, 2005), which can be found in Table 2. The procedure of each stage is described in detail below in section 5.4.

Table 2. *Stages of measure development*

Stages
Determination of the construct to be measured
Generation of the item pool
Reduction of the item pool
Determination of measurement format
Construction of a provisional measure
Preliminary pilot of the measure

5.2 Participants

No participants were needed for the first stages of the measure redevelopment. However, for the preliminary piloting phase, 52 participants were recruited. A power calculation was undertaken to help estimate the number of participants needed for a large effect size using the G*Power statistical power analysis program (Faul, Erdfelder, Lang & Buchner, 2007). A large effect size was chosen due to previous research finding a large effect size, thus suggesting this was reasonable to expect (Allison, Auyeung & Baron-Cohen, 2012). Participants were recruited from an opportunity sample from NHS and non-NHS organisations and participated voluntarily. All volunteers provided written informed consent. The demographic details of participants according to group can be found below. Group 1 consisted of adults with a borderline or mild LD, which represented a 'control group' and Group 2 consisted of adults with a borderline or mild LD *and* ASD, which represented the 'case individuals'.

All information (e.g. level of LD, diagnoses) was self-reported rather than established through assessment or medical files and this was determined by these individuals' involvement in LD/ASD services, key to clinician's judgement, previous classification assigned or similar.

Table 3. Demographic information for each group

	Group 1		**Group 2**	
	N=26		**N=26**	
Age	M 38.60	*SD* 14.85	M 34.00	*SD* 12.81
	N	%	N	%
Gender				
Female	13.00	50.00	15.00	57.69
Male	13.00	50.00	11.00	42.30
LD Type				
Borderline	22.00	15.38	14.00	53.85
Mild	4.00	84.62	12.00	46.15
Ethnicity				
Arab	0.00	0.00	0.00	0.00
Asian / Pacific Islander	0.00	0.00	0.00	0.00
Black	0.00	0.00	3.00	11.54
Caucasian / White	25.00	96.15	22.00	84.62
Hispanic	0.00	0.00	0.00	0.00
Latino	0.00	0.00	0.00	0.00
Multiracial	1.00	3.85	0.00	0.00
Other	0.00	0.00	0.00	0.00

Would rather not say	0.00	0.00	1.00	3.85
Mental Health Difficulty				
Yes	3.00	11.54	13.00	50.00
No	18.00	69.23	10.00	38.46
Prefer not to say	3.00	11.54	3.00	11.54
Other disability				
Yes	8.00	30.77	9.00	34.62
No	13.00	50.00	13.00	50.00
Prefer not to say	5.00	19.23	4.00	15.38

Demographic data reveals that more participants classified themselves as having a mild LD in group 1 than a borderline LD, whereas for group 2, more individuals classified themselves as having a borderline LD than mild, although these differences between groups was not significant ($\chi^2 = 3.52$, $p = .061$). Difference in gender between groups was also not significant ($\chi^2 = 3.10$, $p = .578$).

5.3 Ethical Considerations

Although ethical approval had already been granted by the National Research Ethics Service as above (section 3.4), University ethical approval was also sought for this stage of the project (Appendix 5). This was because NHS recruitment proved difficult and therefore, a request to recruit from non-NHS sources was put forward and accepted. All local Research and Development policies were adhered to when recruiting from non-NHS sources. As well as the ethical considerations described in section 3.4, it was also held in mind that participants might experience using the AQ-10 as distressing due to its

difficulty. Participants were therefore given notice beforehand that they may find it hard and were told that they could stop at any time should they wish. The experimenter also stopped the procedure if it was felt the participant was distressed.

5.4 Procedure

5.4.1 Determination of the construct to be measured.

DeVellis (1991) states that the constructs used within a scale should be based on a theoretical model. Matson, Boisjoli, Gonzalez, Smith and Wilkins (2007) suggest that constructs used in differential diagnosis should also fit the constructs of DSM and ICD criteria. The AQ-10 is made up of ten questions that are based on five constructs: (1) Social Skills (2) Attention Switching, (3) Communication (4) Imagination and (5) Attention to Detail. The authors of the measure state that these constructs have been derived from a theoretical model of ASD based on Wing and Gould's (1979) and Rutter's (1978) 'triad of impairment'. As the AQ-10 had shown to demonstrate good construct validity at this stage, the author of the current study attempted to redesign the questionnaire to retain the constructs whilst making the questions easier to understand and change them in such a way that individuals could give more reliable results. Permission was sought from the authors of the AQ-10 to revise the measure (Appendix 11).

5.4.2 Generation of the item pool.

Where questions could not be reworded to make them easier to understand, based on the above five domains, an alternative list of possible questions was developed that related to these constructs.

5.4.3 Reduction of the item pool.

The author then discussed these alternative questions with the supervisor to check that they accurately reflected what the original constructs were based on. As for the AQ-10, two questions were chosen for each domain of ability with additional 'reserve' questions for the examiner crib sheet.

5.4.4 Determination of measurement format.

Determining the measurement format was guided by a number of ways. Firstly, information from the thematic analysis above was used to find out what participants specifically found difficult about using the AQ-10. Then, a systematic literature search was carried out to review literature on difficulties in using self-report questionnaires with individuals with learning disabilities (see Appendix 12 for the search criteria and table of studies included). These findings were collated and a table of themes was put together to identify the difficulties and suggestions for overcoming these, which guided the redevelopment (Appendix 13).

5.4.5 Construction of a provisional measure.

Based on the above, the measure was constructed, bearing in mind the findings from the literature search and thematic analysis. Once revised, the measure was reviewed by the external supervisor and an expert in the field (an external consultant in LD and ASD) who commented on both the formatting but also the question content to make sure

the re-wording of the questions had not changed the construct that the question was based on. Further revisions were then made based on comments from this.

5.4.6 Piloting.

Once the provisional measure ('AQ-10-R') had been created, it was piloted with a sample of adults. In addition to asking the participants to fill in the AQ-10-R, participants were also given the AQ-10 in its original form to fill in. This was done for two reasons: (1) to act as a comparison for the AQ-10-R and (2) to collect some psychometric data on using the AQ-10 with individuals with borderline or mild learning disabilities. Presentations of the two measures were counterbalanced to reduce order effects.

Mann-Whitney U tests were used to compare means between the groups for both the AQ-10 and AQ-10-R. Internal consistency was assessed using the Kuder-Richardson Formula 20 (KR-20; Kuder & Richardson, 1937). To evaluate discriminative validity, sensitivity and specificity was calculated and receiver operating characteristic (ROC) curves were plotted. Further details of these are provided in the relevant results section. Data was analysed using SPSS for Statistics (Version 19).

5.5 Materials

The pilot study used written packs containing consent forms (Appendix 8), information sheets (Appendix 7), a demographic questionnaire (Appendix 9) and the AQ-10 (Appendix 2) and AQ-10-R questionnaires (Appendix 14). The AQ-10 is readily available on the Internet, free of charge.

6. Phase 2 Results

6.1 Summary of Results from the Measure Redevelopment

The results from the thematic analysis and literature review found ways in which the AQ-10 could be revised. These included changes to the formatting and administration. As a result of these findings, the AQ-10 (Appendix 2) was redesigned (AQ-10-R, Appendix 14) and an Examiner Crib was also designed (Appendix 15).

6.2 Piloting Results

The following results centred on investigating:

4. The usefulness of the adapted and un-adapted AQ-10 in discriminating between adults with LD with and without ASD.
5. The sensitivity and specificity of the adapted and un-adapted AQ-10 for adults with a borderline or mild LD.
6. The internal consistency of the adapted and un-adapted AQ-10 for adults with a borderline or mild learning disability.

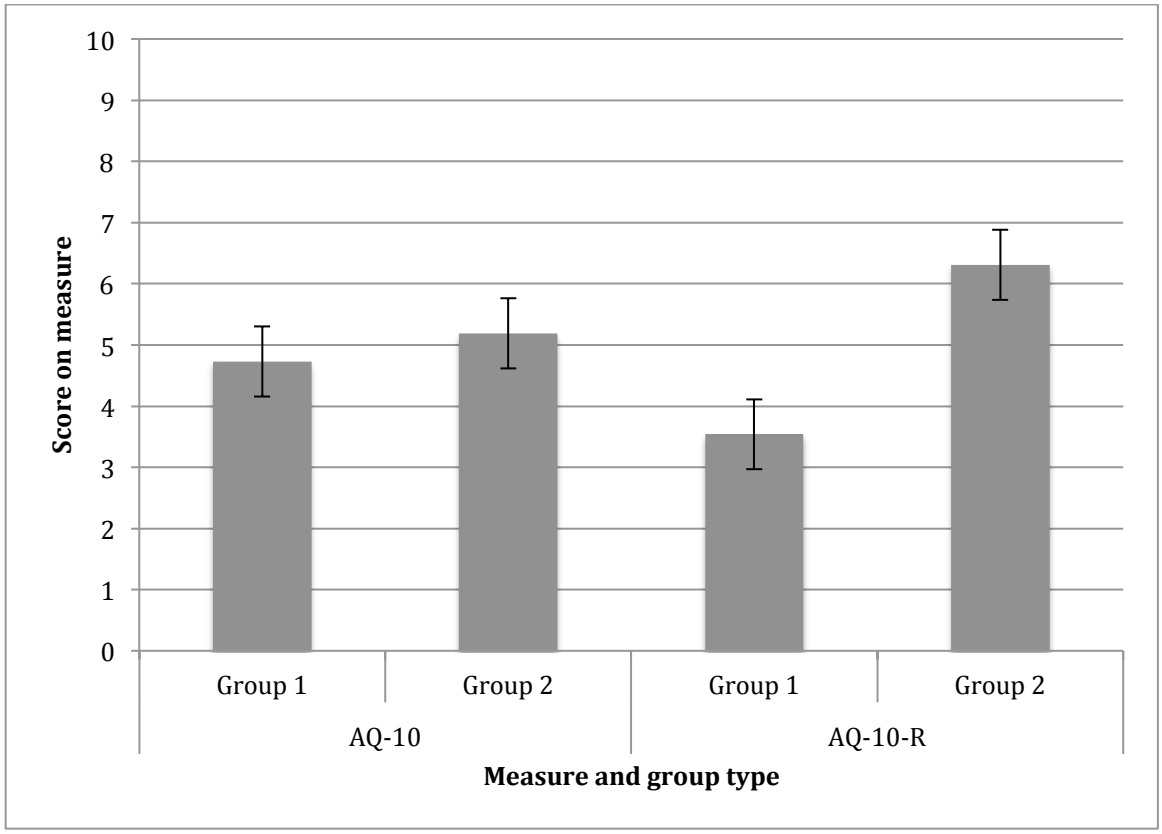
6.3.1 Hypothesis 4 – comparison of means.

Mann –Whitney U tests were conducted to compare the mean scores between case individuals (group 2) and controls (group 1) on both the AQ-10-R and AQ-10. Mann Whitney tests were used, as data was not normally distributed. There were no violations of homogeneity of variance using a non-parametric Levene's Test.

Findings reveal that those with LD and ASD (group 2) (*Mdn* = 6.50) scored significantly higher on the AQ-10-R than people with LD only (group 1) (*Mdn* = 3.00), *U*=94.00, p<.001, *r*= -0.62. Therefore, the null hypothesis can be rejected.

For the AQ-10, findings reveal that those with ASD and LD (group 2) (*Mdn* = 5.50) scored higher than those with LD only (group 1) (*Mdn* = 4.00), however, not significantly, *U*=257.00, p=.130, r= -0.21. For the AQ-10, the null hypothesis cannot be rejected. These findings are presented graphically in Figure 1.

Figure 1: Graph to show mean score on the AQ-10-R and AQ-10 for each group.



6.3.2 Hypothesis 5 – Reliability: internal consistency

The internal consistency of the AQ-10-R was assessed using the Kuder-Richardson Formula 20 (KR-20; Kuder & Richardson, 1937). The results are presented in Table 5. Nunnaly and Bernstein (1994) suggest that a newly developed measure should have a minimum value of .70. Ferketich (1991) states that corrected item-total correlations should range between .30 and .70 for a good scale.

Table 4. Internal consistency of the AQ-10-R compared to the AQ-10.

	AQ-10-R	**AQ-10**	**AQ-10 Result from Allison, Auyeung, Baron-Cohen (2012)**
KR-20 coefficient alpha			
	n=52	*n=52*	*n=449*
	0.67	0.39	0.85*

*Cronbach's alpha

Results reveal the revised measure to have an internal consistency of 0.67 which is below the acceptable value of 0.70 (Nunnaly & Bernstein, 1994). The AQ-10 showed lower significance (alpha = 0.39) on this population compared to Allison, Auyeung and Baron-Cohen (2012) which found a Cronbach's alpha value of 0.85.

6.3.3 Hypothesis 6 – Discriminant Validity: ROC curve analysis and classification statistics

The ability of the AQ-10-R to discriminate between non-ASD (group 1) and ASD (group 2) participants was tested using ROC analysis and via calculating classification

statistics. ROC curves can provide a measure of discriminative validity by plotting and establishing the true positive and false positive rates over a range of potential cut-off scores. Therefore, in this study, ROC curves were utilised for the AQ-10-R and AQ-10 to analyse the measure that would show the most effective discriminant validity for these populations.

The ROC curves can be seen in Figure 2-3 and information relating to area under the curve (AUC) is in Table 6. The aim of the AUC is to estimate the overall measure of discrimination, with a score of 0.9-1.0 representing perfect discrimination, 0.8-0.9 indicating good discrimination, 0.7-0.8 showing fair discrimination, 0.6-0.7 having poor discrimination and anything below 0.6 being worthless. A post-hoc power calculation revealed a sample size needed for an AUC of 0.861 was N=18 (with a minimum of 9 participants in each group).

Figure 2. ROC curve for AQ-10-R

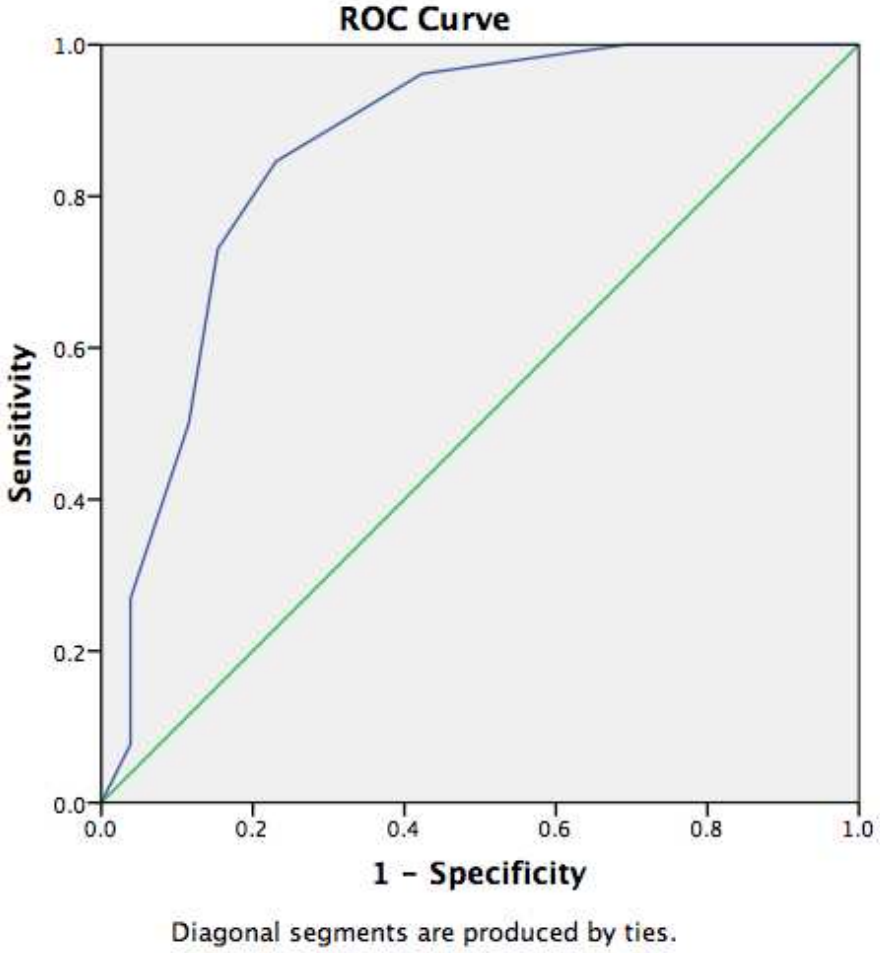
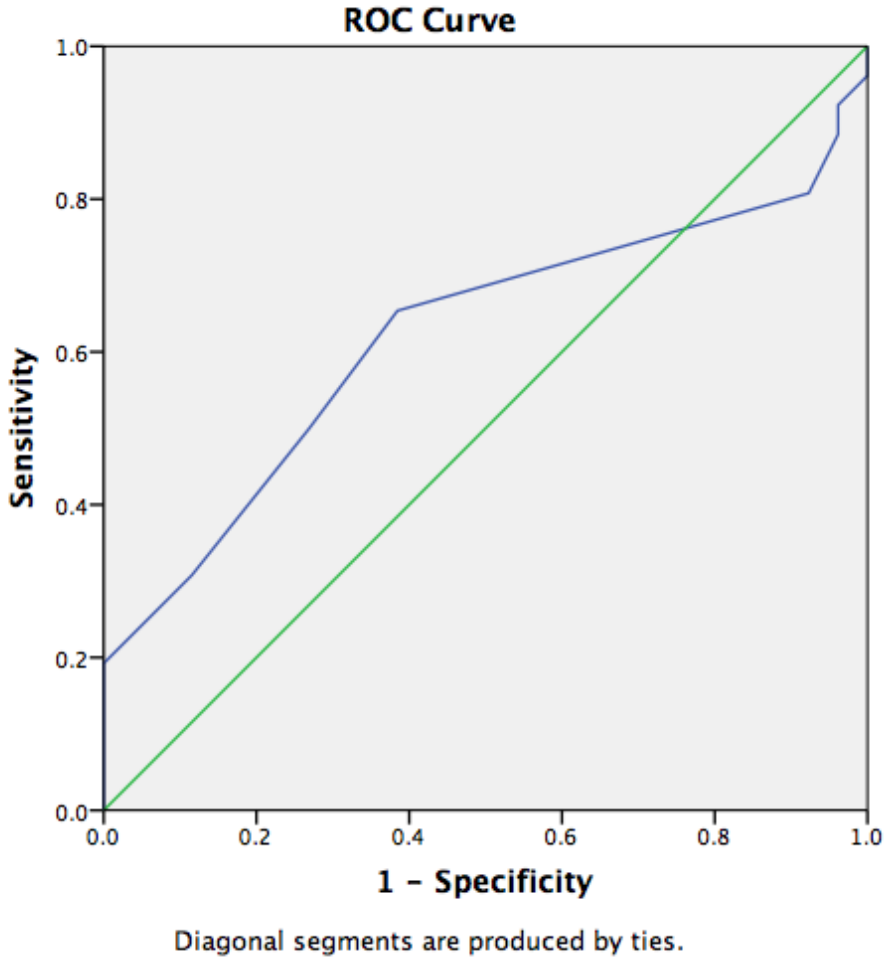


Figure 3. ROC curve for AQ-10



As can be seen in Figure 2, for the AQ-10-R, the curve is above the diagonal 'line of no information' which represents the null hypothesis. This is supported quantitatively in Table 5 and has been found to be highly significant ($p<.001$) with the AUC being 'good'.

For the AQ-10, Figure 3 shows that the curve falls under the null hypothesis line and is non-significant ($p=.138$) with the AUC being in the 'poor' range.

Table 5: AUC for AQ-10-R and AQ-10 measures

				95% Confidence Interval	
	AUC	**Std. Error**	**Significance**	**Lower Bound**	**Upper Bound**
AQ-10-R	0.861	0.054	0.000	0.756	0.966
AQ-10	0.62	0.081	0.138	0.462	0.778

Glasgoe (2005) states that the sensitivity of screening measures should be 70% to 80% and specificity should be 80% in order to reduce over-referrals. However, Lincoln, Nicholl and Flannaghan (2003) suggest that in clinical practice, adequate tools can evidence a sensitivity of 80% and specificity of 60%. In this instance, sensitivity is prioritised over specificity as it would be better to be over-cautious when making initial referrals for further diagnostic assessment. Therefore cut-off scores were chosen that were close to maximum specificity and sensitivity (Youden's Index where sensitivity + specificity – 1; Youden, 1950).

A cut-off for the AQ-10-R was estimated at 5 as this showed the best compromise between sensitivity (0.85) and specificity (0.77). The findings suggest that the AQ-10-R shows good discriminant validity. Allison and colleagues (2012) originally found that the AQ-10 evidenced a sensitivity of 0.88 and specificity of 0.91 for a cut-off of 6. The above findings for the AQ-10 did not find the same results for this population, instead finding sensitivity and specificity to be 'poor'.

7. Discussion

In 2012, NICE guidelines recommended the use of the AQ-10 as a case identification tool for adults with a borderline or mild learning disability (NICE, 2012). However, no research to date has investigated using the AQ-10 with this population. The current research aimed to explore using the AQ-10 screening questionnaire with adults who have a borderline or mild learning disability. Specifically, the study aimed to address two research questions. One aim was to explore the use of the AQ-10 in detecting ASD symptomatology in adults with a borderline or mild learning disability. The second aim consisted of redesigning the measure to investigate whether an easy-read version would be better than the AQ-10 in its original form for the purpose of case identification within this population. The outcome of these aims will be discussed, along with limitations and implications for future clinical practice and research highlighted.

7.1 Qualitative Findings

Although there is a wide literature base that highlights the difficulties of using self-report tools with individuals with learning disabilities (Finaly & Lyons, 2001), it was not known whether these findings would apply to the use of the AQ-10.

The thematic analysis undertaken revealed that those with a borderline or mild learning disability found the AQ-10 difficult to use in its current form. In particular, individuals found the reading level ability required too high, had difficulties in interpreting questions, often taking meanings literally, had difficulties with understanding metaphor and had difficulties in understanding the questions where not enough contextual information was provided. The difficulties in understanding the AQ-10 caused

the participants to guess and rely on help to be able to complete the measure or caused them to acquiesce. Furthermore, completing the AQ-10 was found to have emotional experiences attached to it such as anxiety and fear.

These findings are consistent with the extant evidence base which has found that those with learning disabilities have difficulties with self-report tools due to difficulties understanding unfamiliar content (Duley, Calhorn, Angrim-Delzell & Conroy, 1997; Haynes, Richard & Kubany, 1995; Clark & Watson, 1995; Thorin, Browning & Irvin, 1998; Finlay & Lyons, 2001), difficulties with understanding abstract concepts (Smyley & Elsworth, 1997; Lowe & dePavia, 1998; Malik et al., 1991; McVilly, 1995; Finlay & Lyons, 2001), difficulties in confusing subject-object phrases (Mateson et al., 1984; Sigelman, Budd et al., 1982; Finlay & Lyons, 2001), difficulties with socially reflexive questions (Szivos-Bach, 1993; Mateson et al., 1984; Finlay & Lyons, 2001), difficulties with negatively worded questions (Wehmetey, 1994; Eysenck, 1965; Szivos-Bach, 1993; Finlay & Lyons, 2001); difficulties with quantitative judgements (Sigelman & Schonerock et al., 1981; Biklen & Moseley, 1998; Booth and Booth, 1994; Finlay & Lyons, 2001), difficulties with making direct comparisons (Biklen & Moseley, 1988; Heal & Sigelman, 1995; Finlay & Lyons, 2001) and tendencies towards acquiescence (Kebbell & Hatton, 1999; Sigelma, Budd, Spanhel & Shoenrock 1981, Hael and Sigelman, 1995; Finlay & Lyons, 2001).

7.2 Quantitative Findings

Given the findings that those with a borderline or mild LD felt that the AQ-10 was too difficult to use in its current form, the measure was redesigned following the

principles of measurement development (Oppenheim, 1996; DeVellis, 1991; Rattray & Jones, 2005). An initial pilot of the adapted measure was carried out to investigate some early psychometric properties of the measure.

The findings revealed that amongst those with a borderline or mild learning disability, adults with ASD scored significantly higher (above-cut off) on the adapted measure (AQ-10-R) than those with without ASD. This suggested that higher scores on the AQ-10-R are indicative of ASD symptomatology, consistent with its intended design, and reasonably reliably measured. On the other hand, when examining the AQ-10 in its original format, this pattern was not found, i.e. individuals with LD and ASD did not score highly on the AQ-10 where it would have been expected. This suggests that high scores on the AQ-10 for those with a borderline or mild LD do not indicate ASD symptomatology and therefore, the AQ-10 in its current form does not appear to deliver a reliable estimate of ASD.

Validity was examined by assessing the discriminant validity using ROC curves and classification statistics. Results revealed that for a cut-off score of 5, sensitivity (the ability of the measure to correctly classify those with ASD as having ASD) was 0.85 and specificity (the ability of the measure to correctly identify those without ASD as not having ASD) was 0.77. These findings give support for the discriminative validity of the AQ-10-R and provide some indication of its diagnostic accuracy.

Attempts were also made to compare the psychometric results of the AQ-10-R with the AQ-10. When the AQ-10 was administered, sensitivity and specificity could not be established because the AUC was too low (Glasgoe, 2005; Nicholl & Flannighan, 2003). This suggests that the AQ-10 has ‘poor’ or ‘worthless’ discriminant validity when

using it with adults who have a borderline or mild LD. This is different from the finding of Allison, Auyeung and Baron-Cohen (2012) that found the AQ-10 to have excellent sensitivity and specificity. On the one hand, these differences could be attributable to experimental design or a lack of power, however, it is also likely that the difference is due to the presence of LD as Allison and colleagues excluded those with an IQ below 70 from their study.

On the one hand, these findings suggest that the administration and format of the AQ-10 may impact validity and reliability. However, of note was that the adapted measure, the AQ-10-R evidenced an internal consistency of 0.67, which is below the acceptable level of 0.70 (Nunnaly & Bernstein, 1994). This suggests that although the measure can discriminate ASD from non-ASD individuals, not all items on the measure are correlated with one another. The internal consistency for the un-adapted measure was even lower, at 0.30, which is lower than the 0.85 value found by Allison, Auyeung and Baron-Cohen (2012).

One reason for the low consistency scores could be because the measure is very short (only10 items). Alternatively, the homogeneity of the sample could have impacted the result, as could variation in the test situation (i.e. participants misunderstanding items or getting distracted). Future research should determine test-retest correlations to investigate whether the scale is sensitive to such situational factors.

However, another reason could be that the AQ-10s may not be tapping into ASD alone, and that the test is in fact measuring another construct as well; or that the multi-factorial aspects of ASD itself are being demonstrated. Briggs and Cheek (1986) state that higher internal consistency can mean that only a small, specific part of the construct

is being measured, repeatedly. Therefore, high internal consistency can work against validity due to only a narrow construct being elicited. The lower internal consistencies of the short questionnaires (AQ-10) compared to the and long questionnaire (AQ-50, from which the AQ-10 was derived) may suggest that the shorter measures more readily capture this multi-dimensionality of ASD. For example, structural language skills, although not a defining core feature of ASD in the new DSM-5 or ICD-11 classifications, are a dimension in clinical decision making which may be acting as a latent variable for the AQ-10s but becomes less observable in the AQ-50 due to it having more items.

Additional traits or features that have been shown to correlate or be associated with ASD include implicit mentalising, which is also a key feature of Borderline Personality Disorder, (Frith, 2012), and personality traits such as neuroticism (positively correlated), extraversion and conscientiousness (negative correlated) despite joint factor analysis revealing that autistic traits are independent of these 'Big Five' personality dimensions (Wakabayshi, Baron-Cohen, Wheelwright, 2006). This suggests overlap between different conditions and leaves questions as to whether measures of ASD *traits* are identical to measures of ASD *symptoms.* Therefore a helpful area of future research would be to undertake further discriminate analysis with other conditions, as well as undertaking factor analysis to investigate further the possibility of latent variables.

7.3 Limitations

Several issues should be considered when interpreting the above results. Firstly, over half the participants described themselves as having comorbid mental health difficulties, with rates being higher for the ASD group. This could have influenced the

test results via symptoms being due to the presence of mental health difficulty (or side effect from having a mental health difficulty such as medication) rather than symptoms being due to ASD. However, the questionnaires are designed to be used in clinical settings and therefore the sample used in this study is reflective of the realties that clinicians face, particularly as Sappok et al., (2014) state those with LD and / or ASD are amongst the most medicated groups in society.

The second issue is that severity of LD differed between the groups with the ASD group consisting of more adults with borderline than mild, compared to the LD group which consisted of more individuals with mild LD. This is in contrast to the literature that finds more severe levels of LD in those with ASD (Cooper, Smiley, Morrison, Williamson, & Allan, 2007; de Bildt, Sytema, Kraijer, & Minderaa, 2005; Sappok et al., 2010). One reason could be that diagnoses were self-reported, rather than formally assessed with a standardised IQ assessment. Although all participants were recruited from settings where they had to have an LD diagnosis to access support, it could be that many were unaware of the level of LD diagnosed. This issue also means that caution must be used when drawing conclusions as it could be that some individuals could have had more severe needs than a borderline or mild learning disability may infer. However, to some extent, this was screened for during the recruitment as those individuals in the moderate range of LD are reported to have difficulties with language. Participants who were unable to read were not included in this study.

A further limitation relating to the sample concerns the issue of gender. Research suggests that males are more likely to be diagnosed with ASD than females (Fombonne, 2003). Some suggest that this is due to biological differences, however, emerging

theories acknowledge that due to construct of ASD being developed from a male presentation, the female characterisation of ASD and is less well understood, leaving females to be less likely referred for diagnostic assessment (Dworzynski, Ronald, Bolton, & Happé, 2012).

Key differences between genders that have been found include females being more likely to engage in social conversations (Attwood, 2006), as well as more likely to use strategies that hide social-communication difficulties (Gould, Ashton & Smith, 2011), making the social interaction possibly less valid. Furthermore, research suggests females are more likely to display pro-social behaviour (Divorzynski et al., 2012) and experience more mental health difficulties associated with internalising difficulties (Solomon, Miller, Taylor, Hinshaw & Carter, 2012). Additionally, Hsiao, Tseng, Huang and Gau (2013) suggest that ASD presents differently across the lifespan for females in particular with them struggling to mask symptoms when being faced with pressures of social acceptance, for example during adolescence.

Therefore, future research should investigate whether the AQ-10-R is disadvantageous to females and whether the measure should be adapted to include multiple cut-offs to account for both gender and lifespan / developmental trajectory issues.

Concerns regarding the challenge of conducting qualitative research with people with communication or learning difficulties should also be considered (Stalker, 1998). Only two master themes were generated from the thematic analysis. Although the participants taking part in the focus group were familiar with giving their opinions on documents (as they were volunteers for the Trust in consulting on the readability of

documents), there may still have been some difficulties with gathering data which could have lead to the 'thinness' of the thematic analysis findings. Some of the quieter voices were less able to be heard in the focus group and the author perceived some degree of acquiescence amongst the group members. A way of increasing the robustness or quality of the thematic analysis would have been to carry out a number of focus groups or to perhaps carry out interviews on an individual basis.

A further issue to consider is the appropriateness of the mixed-methods approach in addressing the research objectives. To some extent, the integration of both qualitative and quantitative data has allowed for triangulation of the issue of using the AQ-10 with adults who have a borderline or mild learning disability. In other words, the qualitative phase allowed for rich narratives of experts by experience of using of the AQ-10, whilst the quantitative statistics allowed for these issues to be empirically tested.

One could argue that the integration of both qualitative and quantitative methods is not appropriate as a lack of uniform methodology leads to difficulties with drawing conclusions. Furthermore, postpositivists and constructivists would argue that a mixed-methods design is not possible due to seemingly incompatible paradigms (Guba & Lincoln, 1994).

However, the current research takes a more pragmatic stance in seeing different methodologies as being a tool-kit of which to pick the appropriate apparatus to find results that are helpful. A limitation of this approach is that 'what is helpful' can be different for different people. Therefore, the current study is positioned then as merely an 'expansion' of the issues, with the aim of extending the breadth and range of enquiry (Greene & Graham, 1989).

7.4 Implications

Many individuals with LD also have ASD (Matson & Shoemaker, 2009) and as such there is a need for appropriate case identification tools for this population. Without suitable screening tools, ASD can go undetected with under diagnosed comorbidity leading to higher rates of pharmacological use, additional mental health difficulties and lower quality of life (Sappok et al., 2014). However, there is a paucity of adequate screening tools for this population.

The above results gives promise in showing that simple adaptations (such as making the AQ-10 into an 'easy-read' measure) can improve its ability to screen for ASD symptomatology in those with a borderline or mild LD. This finding has implications both in clinical practice and for future research.

The results suggest that there is not a 'one size fits all' approach to the case identification of ASD in adults. NICE (2012) suggest that the AQ-10 should not be used with those who have a moderate or severe LD but perhaps the guidelines should go further in stating that the AQ-10 should not be used in those with a borderline or mild LD, unless presented in easy-read format. The AQ-10-R provides a first step in what such a format could look like and has evidenced good psychometric properties in initial piloting. It would be useful to increase the sample size and carry out a full psychometric validation study.

As well as the above findings having implications for clinical practice, the findings also suggest areas in which future research may be helpful. The influence of the changing diagnostic criteria of ASD recognises ASD symptoms across the IQ range.

Therefore, there may be an increasing need for case identification instruments that identify ASD across the different LD categories. This brings to light an issue of the heterogeneity of ASD across the IQ range.

Matson an Shoemaker (2009) believe that the symptomatology of ASD in those with a LD is qualitatively different from the symptomatology in ASD in those with IQs above 70. This would suggest that therefore not only does the administration, or design of the measure need adapting, but also perhaps the constructs themselves. The current findings suggest that the issue of construct validity may be less of a problem for individuals within the borderline or mild ranges as the AQ-10-R showed good discriminative validity. Hurley and Levitas (2007) state that more attention is needed to individuals with comorbid ASD and LD, as the majority of researchers tend to focus on ASD alone. The current study echoes this and shows that researchers will need to be more attentive to the needs of those with comorbid LD/ASD when investigating case identification in the future.

8. Conclusions

Individuals with learning disabilities are at risk of ASD, which is under recognised in adults (La Malfa et al, 2004; Sappok, et al. 2014). In recent years there has been an acknowledgement that autism is 'growing up' and as such, recommendations have been put forward regarding the case identification and assessment of ASD in adults. The AQ-10 is the recommended screening tool of choice for those with a borderline or mild LD according to NICE guidelines (2012) however it has not been developed with these individuals in mind. The AQ-10-R, developed in consultation with experts by experience,

proved to be a better screening measure than the AQ-10 with this population. A full psychometric evaluation is needed, however, the revised measure shows promise in being a means of guiding front line clinicians in making decisions regarding referrals for diagnostic ASD assessments.

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Appendix 1: Table of excluded studies from Part A.

Study	*Why excluded*
Screening Tools	
Allison, C, Auyeung, B. & Baron-Cohen, S. (2012). Towards brief red flags for autism screening: the short autism spectrum quotient and the short quantitative checklist in 1000 cases and 3000 controls. *Journal of the American Academy of Child and Adolescent Psychiatry, 51,*202-212.	IQ above 70
Baron-Cohen, B., Wheelwright, S., Skinner, R., et al. (2001). The Autism-spectrum Quotient (AQ): evidence from Asperger syndrome /high functioning autism, males and females, scientists and mathematicians. *Journal of Autism and Developmental Disorders, 31,* 5-17.	IQ above 70
Brugha, T.S., MacManus, S., Smith, J., et al. (2012). Validating two survey methods for identifying cases of autism spectrum disorder among adults in the community. *Psychological Medicine, 42,* 647-656.	IQ above 70
Ferriter, M., Hare, D., Bendall, P., et al (2001). Brief report: assessment of a screening tool for autistic spectrum disorders in adult population. *Journal of Autism and Developmental Disorders, 3,* 351-353.	No information about LD.
Garfin, D.G., McCallon, D., (1988) Validity and reliability of the autistic rating scale with autistic adolescents. *Journal of Autism and Developmental Disorders, 18, 376-378.*	Adolescents only.
Kurita, H., Koyama, T. & Osada, H. (2005). Autism-spectrum quotient – Japanese version and its short forms for screening normally intelligent persons with PDD. *Psychiatry and Clinical Neurosciences, 59,* 490-496.	IQ above 70
Matson, J.L., Baglio, C.S., Smiroldo, B.B., Hamilton, M. & Packlowskyi, T. (1996). Characteristics of Autism as Assessed by the Diagnostic Assessment for the Severly Handicapped-II (DASH-II). *Research in Developmental Disabilities, 17, 2,* 135-143.	Not a measure specific of Autism.
Mesibov, G.B., Schopler, E., Schaffer, B, et al. (1989). Use of the childhood autism rating scale with autistic adolescents and adults. *Journal of American academy of Child and Adolescent Psychiatry, 28,* 538-514.	Mean age of sample too low.

Nylander, L., Gillberg, C (2001). Screening for autism spectrum disorders in adult psychiatric out-patients: a preliminary report. *Acta Psychiatrica Scandinavica, 103,* 428-434.	Learning disability excluded.
Sappok, T., Heinrich, M. & Diefenbacher, A. (2014). Psychometric properties of the Autism Checklist (ACL) in adults with intellectual disability. *Journal of Psychiatric Praxis, 41, 1,* 37-44.	Only available in German
Wakabayashi, A., Baron-Cohen, S., Wheelwright, S. et al (2006). The Autism-Spectrum Quotient in Japan: a cross-cultural comparison. *Journal of Autism and Developmental Disorders, 36,* 263-270.	IQ above 70
Woodbury-Smith, M.R., Robinson, J., Wheelwright, S., et al (2005). Screening adults for Asperger syndrome using the AQ: A preliminary study of its diagnostic validity in clinical practice. *Journal of Autism and Developmental Disorders, 35,* 331-335.	IQ not stated but LD was an exclusion criteria.

Assessment Tools

Brugha, T.S., MacManus, S., Smith, J., et al. (2012). Validating two survery methods for identifying cases of autism spectrum disorder among adults in the community. *Psychological Medicine, 42,* 647-656.	No IQ information available No psychometric data reported
Baron-Cohen, S., Wheelwright, S., Robinson J., et al. (2005). The Adult Asperger Assessment (AAA): a diagnostic method. *Journal of Autism and Developmental Disorders, 35,* 807-819.	LD an exclusion criteria.
Dziobek, I., Fleck, S., Kalbe, E. et al (2006). Introducing MASC: a movie for the Assessment of Social Cognition. *Journal of Autism and Developmental Disorders, 36, 623-636.*	IQ not stated but thought to be in normal range. Not a measure of ASD per se.
Gillberg, C., Rastam. M. (2011). The Asperger Syndrome (and high functioning autism) Diagnostic Interview (ASDI): a preliminary study of a new structured clinical interview. *Autism, 5,* 57-66.	Asperger only IQ above 70
Lord, C., Risi, S., Lambrecht, L., et al (2000). The Autism Diagnostic Observation Schedule –Generic: a standard measure for social and communication deficits associated	No IQ ranges reported but thought to be above 70.

with the spectrum of autism. *Journal of Autism and Developmental Disorders, 30,* 205-223.	
Ritvo, R.A., Ritvo, E.R., Gutherie, D. et al (2008). A scale to assist the diagnosis of autism and Aspergers disorder in adults (RAADS): A pilot study. *Journal of Autism and Developmental Disorders, 38, 213-223.*	IQ above 70
Ritvo, R.A. Ritvo, E.R. Gutherie et al (2011). The Rivto Autism Asperger Diagnostic Scale – Revised (RADDS-R): a scale to assist the diagnosis od autism spectrum disorder in adults: an international validation study. *Journal of Autism and Developmental Disorders, 41,* 1076-1089.	IQ above 80
Bolte, S., Poustka, F. & Constantino, J. N. (2008) Assessing autistic traits: cross- cultural validation of the Social Responsiveness Scale (SRS). *Autism Research*, *1*, 354–363.	Children only
Buitelaar, J. K., Van der Gaag, R., Klin, A., *et al.* (1999) Exploring the boundaries of pervasive developmental disorder not otherwise specified: analyses of data from the DSM-IV autistic disorder field trial. *Journal of Autism and Devlopmental Disorders*, *29*, 33–43.	Only small number of sample adults
Capone, G. T., Grados, M. A., Kaufmann, W. E., *et al.* (2005) Down syndrome and comorbid autism-spectrum disorder: characterization using the Aberrant Behavior Checklist. *American Journal of Medical Genetics*, *134A*, 373–380.	Children only
Garfin, D. G. & McCallon, D. (1988) Validity and reliability of the Childhood Autism Rating Scale with autistic adolescents. *Journal of Autism and Developmental Disorders*, *18*, 376–378.	Children only
Hellings, J. A., Nickel, E. J., Weckbaugh, M., *et al.* (2005) The Overt Aggression Scale for rating aggression in outpatient youth with autistic disorder: preliminary findings. *Journal of Neuropsychiatry and Clinical Neurosciences*, *17*, 29–35.	Children only
Lecavalier, L. & Aman, M. G. (2006) Validity of the Autism Diagnostic Interview-Revised. *American Journal of Mental Retardation*, *111*, 199–215.	Children only
Le Couteur, A. & Rutter, M. (1989) Autism Diagnostic Interview: a standardized investigator-based instrument. *Journal of Autism and Developmental Disorders*, *19*,	Children only

363–387.	
Prosser, H., Moss, S., Costello, H., *et al.* (1998) Reliability and validity of the mini PAS-ADD for assessing psychiatric disorders in adults with intellectual disability. *Journal of Intellectual Disability Research*, *42*, 264–272.	Autism sample too small
Reading, S. & Richie, C. (2007) Documenting changes in communication behaviours using a structured observation system. *Child Language Teaching and Therapy*, *23*, 181–200.	Children only
Rojahn, J., Matson, J. L., Lott, D., *et al.* (2001) The Behaviour Problems Inventory: an instrument for the assessment of self-injury, stereotyped behaviour, and aggression/destruction in individuals with developmental disabilities. *Journal of Autism and Developmental Disorders*, *31*, 577–588.	Autism sample too small
Sturmey, P., Burcham, K. J. & Perkins, T. S. (1995) The Reiss Screen for Maladaptive Behaviour: its reliability and internal consistencies. *Journal of Intellectual Disability Research*, *39*, 191–195.	No psychometric data

Appendix 2: The AQ-10 Questionnaire

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Appendix 3: National Research Ethics Service confirmation to proceed.

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Appendix 4: NHS Research and Development Approval

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Appendix 5: University Ethics approvals

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Appendix 6: Information sheet: Focus group

Information sheet for participants – Focus Group, Version 3, 03/03/2014

[redacted]

Canterbury Christ Church University

Salomons Campus at Tunbridge Wells

Using the AQ-10 with adults who have a borderline or mild learning disability – a possible measure adaptation

Would you like to take part in some research? Before you decide, read the information below. It will tell you what the research is about and what it will involve.

Who am I?

My name is Lizzie Kent and I am a trainee clinical psychologist. I am carrying out this research as part of my training. The research is being overseen by Dr Elizabeth Kilbey, who is also a clinical psychologist.

What is the study about?

Sometimes doctors find it hard to notice if an adult has autism spectrum disorder (ASD) because it is hard to see the symptoms. It is even harder when the adult has a learning disability.

Some people have made a questionnaire that might help doctors detect ASD. We want to find out if this questionnaire is any good.

What will happen in this study?

1. You will be given a questionnaire to fill in that asks you questions about ASD
2. You, and the other people in the group, will be asked your opinion about whether you think the questionnaire you filled in was good or not and if you have any ideas to make it better. We may tape record you so we don't miss anything important you say.
3. We will ask you to fill out a form which asks about your age, gender and if you have any disabilities.

What is good about taking part?

This project will help us to find better ways of screening for ASD in people who have a learning disability.

Will what I say be private?

Yes! All the information that is collected will be locked away safely. We may include your answers in the final write-up, but we will not put your name anywhere in the report.

Do I have to take part?

No! It is your choice. If you do want to take part, we will give you a consent form to sign. If you want to take part, but change your mind in the middle, that's okay. You can back out at any time

Information sheet for participants – Focus Group, Version 3, 03/03/2014

[redacted]

Canterbury Christ Church University

Salomons Campus at Tunbridge Wells

Who is organising and funding the research?

This research is funded by Canterbury Christ Church University.

Who has reviewed the study?

All research in the NHS is looked at by a group of people called a Research and Ethics Committee. This study has been reviewed by them and they have given permission for it to go ahead.

What if I have a complaint?

If you are not happy with the research you can talk to Professor Paul Camic, head of research at Canterbury Christ Church University who will be able to help you.

Who do I contact for more information?

If you have questions, you can leave a message for me on a 24-hour answerphone on 03330117070. Please say that the message is for me (Lizzie Kent) and leave a telephone number so that I can get back to you, or contact me on email: l.c.kent153@canterbury.ac.uk

Contacts

[redacted]

Lizzie Kent
Trainee Clinical Psychologist

Canterbury Christ Church University
Department of Applied Psychology
Salomons Campus
Broomhill Road Southborough
TN3 0TG

Tel: 0333 0117070

Prof. Paul Camic
Professor of Psychology & Public Health;
Research Director

Salomons Centre for Applied Psychology
Canterbury Christ Church University
Broomhill Road
Tunbridge Wells, Kent
TN3 0TF UK

tel: (44) 03330 117 11

Appendix 7: Information sheet: Piloting

Information sheet for participants – Piloting, Version 3, 03/03/2014

Canterbury Christ Church University

Salomons Campus at Tunbridge Wells

Using the AQ-10 with adults who have a borderline or mild learning disability – a possible measure adaptation

Would you like to take part in some research? Before you decide, read the information below. It will tell you what the research is about and what it will involve.

Who am I?

Hello. My name is Lizzie Kent and I am a trainee clinical psychologist. I am carrying out this research as part of my training. The research is being overseen by Dr Elizabeth Kilbey, who is also a clinical psychologist.

What is the study about?

Sometimes doctors find it hard to notice if an adult has autism spectrum disorder (ASD) because it is hard to see the symptoms. It is even harder when the adult has a learning disability.

Some people have made a questionnaire that might help doctors detect ASD. We want to find out if this questionnaire is any good.

What will happen in this study?

1. We will ask you to fill out a form which asks about your age, gender and if you have any disabilities. If you cannot remember if you have been diagnosed with a disability, we would like permission to check your medical file.
2. You will be given two questionnaires to fill in that asks you questions about ASD. These questionnaires will take 10 minutes each.

What is good about taking part?

This project will help us to find better ways of screening for ASD in people who have a learning disability.

Will what I say be private?

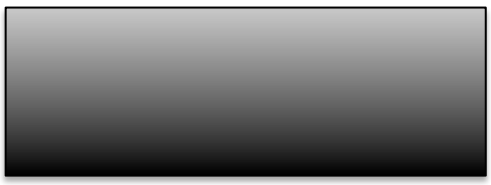
Yes! All the information that is collected will be locked away safely. We may include your answers in the final write-up, but we will not put your name anywhere in the report.

Do I have to take part?

No! It is your choice. If you do want to take part, we will give you a consent form to sign. If you want to take part, but change your mind in the middle, that's okay. You can back out at any time.

Who is organising and funding the research?

Information sheet for participants – Piloting, Version 3, 03/03/2014



Canterbury Christ Church University

Salomons Campus at Tunbridge Wells

This research is funded by Canterbury Christ Church University.

Who has reviewed the study?

All research in the NHS is looked at by a group of people called a Research and Ethics Committee. This study has been reviewed by them and they have given permission for it to go ahead.

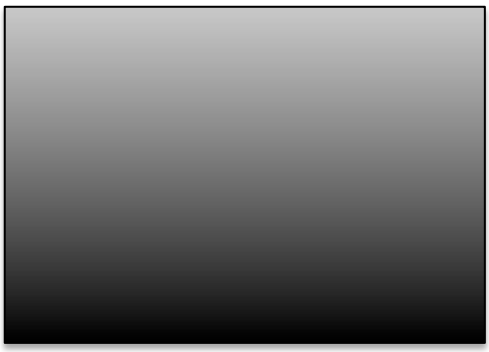
What if I have a complaint?

If you are not happy with the research you can talk to Professor Paul Camic, head of research at Canterbury Christ Church University who will be able to help you.

Who do I contact for more information?

If you have questions, you can leave a message for me on a 24-hour answerphone on 03330117070. Please say that the message is for me (Lizzie Kent) and leave a telephone number so that I can get back to you, or contact me on email: l.c.kent153@canterbury.ac.uk

Contacts



Lizzie Kent
Trainee Clinical Psychologist

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Prof. Paul Camic
Professor of Psychology & Public Health;
Research Director

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Canterbury Christ Church University
Broomhill Road
Tunbridge Wells, Kent
TN3 0TF UK

tel: (44) 03330 117 11

Appendix 8: Consent form

[redacted]

Canterbury Christ Church University

Salomons Campus at Tunbridge Wells

Participant Identification Number for this study: [

CONSENT FORM

Title of Project: Using the AQ-10 with adults who have a learning disability

Name of Researcher: Elizabeth Kent, Trainee Clinical Psychologist

Please initial in box

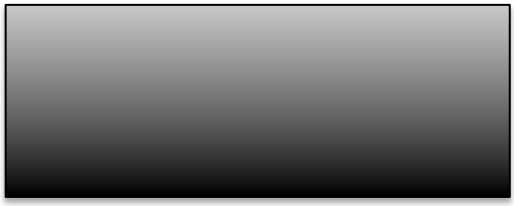
1. I confirm that I have read and understand the information sheet dated 20/01/2014 for the above study. I have had the chance to ask questions and I got good answers to these.	
2. I understand that I do not have to participateif I do not want to and that I am free to stop at any time without giving any reason, without my care being affected.	
3. I understand that anonymised data collected during the study may be looked at by the lead supervisors [redacted] give permission for these individuals to have access to my data.	
4. I give permission for the researchers Lizzie Kent an[redacted] [redacted] to access my medical records and understand that my records will be accessed only for confirmation of diagnosis and no other reason.	
5. I agree to take part in the above study.	
7. I acknowledge that anonymised data from this study will be published.	

Department of Applied Psychology
Faculty of Social and Applied Sciences

David Salomons Estate
Broomhill Road Southborough Tunbridge Wells Kent TN3 0TG (UK)
Tel +44 (0) 1892 515152 Fax +44 (0) 1892 539102
www.canterbury.ac.uk

IRAS ProjectID: **146916**

Consent Form – Version 2 – 20/01/2014



Canterbury Christ Church University

Salomons Campus at Tunbridge Wells

Please print name	
Address	
Contact Phone Number	
Email address	

Please sign here:

Name of Participant	Date	Signature
Name of Person taking consent	Date	Signature

Department of Applied Psychology
Faculty of Social and Applied Sciences

David Salomons Estate
Broomhill Road Southborough Tunbridge Wells Kent TN3 0TG (UK)
Tel +44 (0) 1892 515152 Fax +44 (0) 1892 539102
www.canterbury.ac.uk

Appendix 9: Demographics questionnaire:

Participant ID:

Canterbury Christ Church University

Salomons Campus at Tunbridge Wells

DEMOGRAPHIC QUESTIONNAIRE

1. **Are you** (please circle)**:** male female

2. **What is your date of birth?** _____

3. **How would you classify yourself** (please circle)**?**

Arab	Asian / Pacific Islander	Black
Caucasian / White	Hispanic	Latino
Multiracial	Would rather not say	Other

4. **What is your highest level of education completed** (please circle)?

No schooling	Primary School	Secondary School
6th form college	Vocational education	University

5. **Do you have a learning disability** (please circle)**?**

No
Yes.
If yes, please circle which type:
Borderline
Mild
Moderate
Severe

6. **Have you been diagnosed with** (please circle)**:**

Autism Spectrum Disorder (ASD)
Asperger Syndrome

7. **Have you been diagnosed with a mental health difficulty?**

   Yes
   No
   Prefer not to say

8. **Would you consider yourself to have any other disability?**

   Yes
   No
   Prefer not to say

Appendix 10: Focus group code book

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Appendix 11: Email from author of AQ-10

>>> Professor Simon Baron-Cohen <sb205@cam.ac.uk> 09/06/2014 10:23 >>>
dear [redacted]. sorry i missed this email. i hope this project is progressing well. do keep me posted on any results. best, simon bc

On 2013-12-19 16:52, [redacted] wrote:

Dear Prof Baron-Cohen,

My colleague [redacted] contacted you a while ago to raise a query about the use of the AQ10 with individuals with mild and borderline LD. [redacted] and I have for the past 2 years been setting up an running an Adult ASD assessment service in [redacted] NHS Trust. We routinely use the EQ, AQ and AQ10 as needed. We have found that for individuals with mild to moderate LD the AQ10 can present with challenges for them in terms of reading and understanding the items.

Therefore we have liaise with Salomons Centre Clin Psych training programme and have recruited a clinical psychology trainee to investigate this issue for their major research project. A brief description of their project is provided below. The study proposes to examine whether the AQ10 is sensitive to the presence of ASD symptoms in individuals with mild to moderate LD. And then consider whether any adaptations to the wording of the items, or adapting to a semi-structured interview format would improve sensitivity.

I wanted to notify you about the proposed research and ask whether you have any comments or considerations that you feel should be taken in to account at this proposal stage.

I thank you in advance for your time and will gladly notify you of the progress of the study

best wishes

[redacted]
> Dr Elizabeth Kilbey
> Consultant Clinical Psychology
> Adult ASD Assessment Service, Oxleas NHS Trust
>
> The introduction of the Autism Act (2009) identified the need for
> better services for adults with autism spectrum disorder (ASD). The
> National Institute for Clinical Excellence (NICE) reviewed its
> guidelines in 2012 which results in new recommendations for the
> recognition, referral, diagnosis and management of adults on the
> autism spectrum. They identified a need for a screening tool that

> could be used in clinical practice to help support the decision for a
> full diagnostic assessment. The AQ-10 was recommended as it
> represented the best compromise between sensitivity, specificity,
> availability and ease (Allison, Auyeung, Baron-Cohen, 2012).
>
> It has been estimated that a high number of individuals with ASD also
> have a learning disability; however the AQ-10 is not normed or
> validated for adults with a learning disability. Despite this, NICE
> have recommended using the AQ-10 with adults who have a borderline or
> mild learning disability.
>
> The aim of this project is to investigate whether the existing AQ-10
> is adequate for the need of screening adults with a borderline or mild
> learning disability who may have ASD. Based on the outcome of this,
> the project will consider adaptations that could be made to the AQ-10
> that will improve its accessibility and sensitivity to the presence of
> ASD symptomatology in adults with a diagnosis of borderline or mild
> learning disability and autism.
>
> **********
> [redacted]
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Appendix 12: Phase 2 Literature Review

1. Literature Review – Phase 2 measure redevelopment.

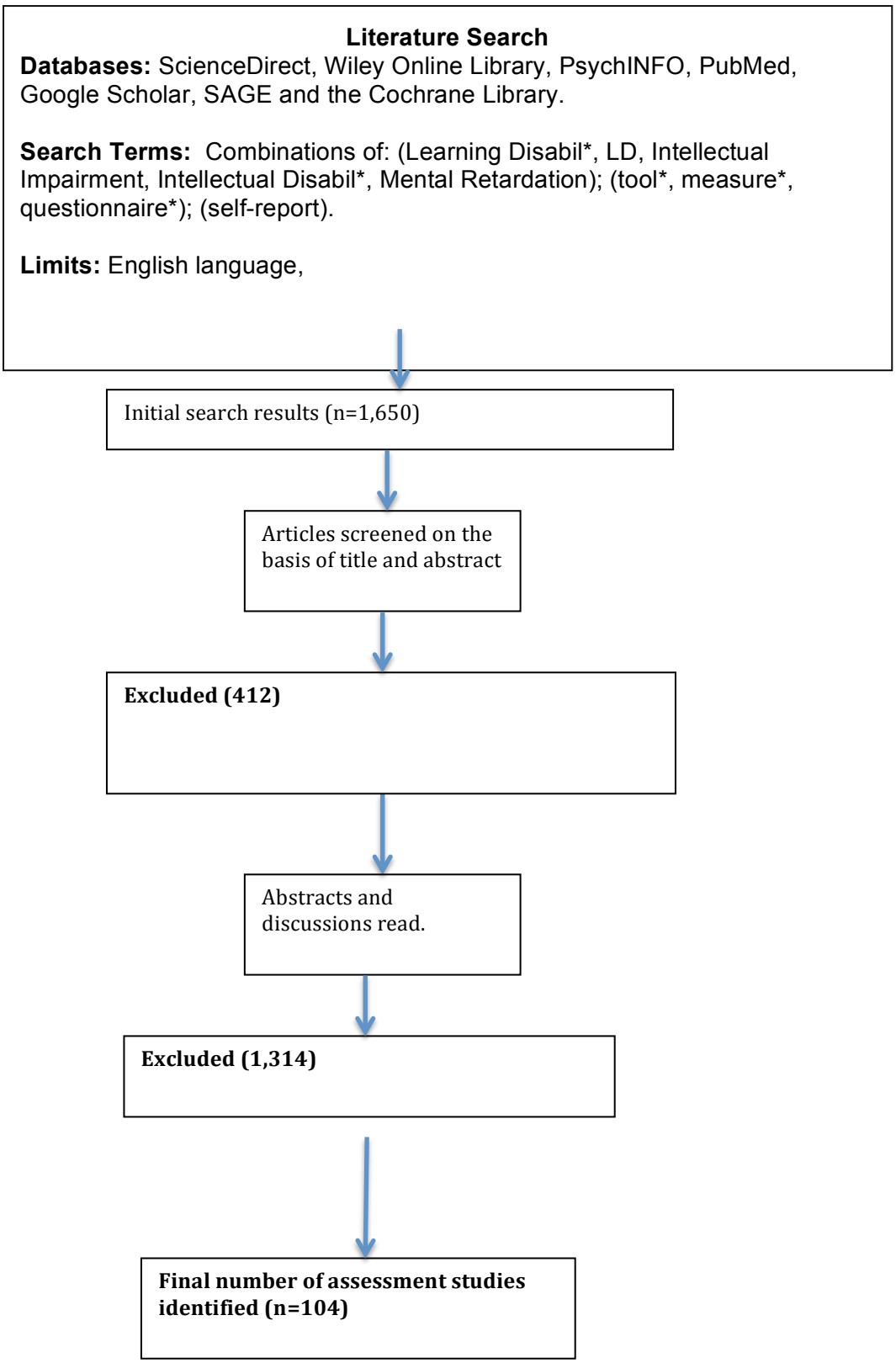
1.1 Aims

The aim of the review was to bring together the extant literature concerning difficulties in using self-report questionnaires with individuals who have learning disabilities.

1.2 Review Methodology

The literature review used the following databases to search for relevant papers: ScienceDirect, Wiley Online Library, PsychINFO, PubMed, Google Scholar, SAGE and the Cochrane Library. Hand searches were also carried out following identification of more papers not found in the databases. A representation of the search strategy is presented below.

The review did not use strict exclusion or inclusion criterias. This was because it was important to get as wide breadth as possible of possible methodological issues in using self-report measures with people with learning disabilities.


Literature Search
Databases: ScienceDirect, Wiley Online Library, PsychINFO, PubMed, Google Scholar, SAGE and the Cochrane Library.
Search Terms: Combinations of: (Learning Disabil*, LD, Intellectual Impairment, Intellectual Disabil*, Mental Retardation); (tool*, measure*, questionnaire*); (self-report).
Limits: English language,
Initial search results (n=1,650)
Articles screened on the basis of title and abstract
Excluded (412)
Abstracts and discussions read.
Excluded (1,314)
Final number of assessment studies identified (n=104)

Difficulty of interest	Papers
Review paper	Finlay, W & Lyons, E. (2001). Methodological issues in interviewing and using self-report questionnaires with people with mental retardation. *Psychological Assessment, 13,* 319-335. doi: 10.1037/1040-3590.13.3.319.
Quantitative judgements	Sigelman, C.K., Shoenenrock, C.J., Winer, J.L., Spanhel, C.L., Hromes, S.G., Martin, R.W., Budd, E.C., & Bensberg, G.J. (1981). Issues in interviewing mentally retarded persons: An empirical study. In R.H. Bruninks, C.E. Meyers, B.B., Sigford, & K.C. Lakin (Eds). *Deinstitutionalization and community adjustment of mentally retarded people.* Washington DC: American Association of Mental Deficiency.
	Biklen, S.K., & Moseley, C.R., (1988). Are you retarded? No I'm Catholic: Qualitative methods in the study of people with severe handicaps. *Journal for the Association of People with Severe Handicaps, 13,* 155-162.
	Booth, T., & Booth, W. (1994a). The use of depth interviewing with vulnerable subjects: Lessons from a research study of parents with learning disabilities. *Social Science and Medicine, 39,* 415-424. doi:10.1016/0277-9536(94)90139-2.
	Booth, T., & Booth, W. (1994b). *Parenting under pressures: Mothers and fathers with learning difficulties*. Buckingham England: Open University Press.
	Booth, T., & Booth, W. (1996). Sounds of silence: Narrative research with inarticulate subjects. *Disability and Society, 11,* 55-69. doi:10.1080/09687599650023326
	Flynn, M.C. (1986). Adults who are mentally handicapped as consumers: Issues and guidelines for interviewing. *Journal of mental Deficiency Research, 30,* 369-377. Retrieved from: http://www.ncbi.nlm.nih.gov/pubmed/3806664?dopt=Abstract

	Lindsay, W.R., & Michie, A.M. (1988). Adaptation of the Zung self-rating anxiety scale for people with a mental handicap. *Journal of Mental Deficiency Research, 32,* 485-490. doi: 10.1111/j.1365-2788.1988.tb01440.x
	Malik, P.B., Ashton-Schaeffer, C. & Kleiber, D.A. (1991). Interviewing young adults with mental retardation: A seldom used research methods. *Therapeutic Recreation Journal, 25,* 60-73. Retrieved from: http://js.sagamorepub.com/trj/article/view/4560.
	Matson, J.L. & Frame, C.L. (1986). *Psychopathology among mentally retarded children and adolescents.* California: SAGE.
	Moss, S., Patel, P., Prosser, H., Goldberg, D., Simpson, N, Rowe., S & Lucchino, R. (1993). Psychiatric morbidity in older people with moderate and severe learning disability: Development and reliability of the patient interview (PAS-ADD). *British Journal of Psychiatry, 163,* 359-367. doi: 10.1192/bjp.163.4.471
	Wyngaarden, M. (1981). Interviewing mentally retarded persons: Issues and strategies. In R.H. Bruininks, C.E., Meyers, B.B., Sigford, & K.C. Lakin (Eds). *Deinstitutionalization and community adjustment of mentally retarded people.* Washington DC: American Association of Mental Deficiency.
Direct comparison	Biklen, S.K., & Moseley, C.R., (1988). Are you retarded? No I'm Catholic: Qualitative methods in the study of people with severe handicaps. *Journal for the Association of People with Severe Handicaps, 13,* 155-162.
	Heal, L.W., & Sigelman, C.K. (1995). Response biases in interviews of interviews of individuals with limited mental ability. *Journal of Intellectual Disability Research, 39,* 331-340. doi: 10.1111/j.1365-2788.1995.tb00525.
	Matson, J.L. & Frame, C.L. (1986). *Psychopathology among mentally retarded children and adolescents.* California: SAGE.
	Smyley, S.R., & Ellsworth, K. (1997). Interviewing clients: A project to explore client views about a change in service

	provision. *British Journal of Learning Disabilities, 2,* 64-67. doi: 10.1111/j.1468-3156.1997.tb00012.
	Mateson, J.L., Kazdin, A.E., & Senatore,V. (1984). Psychometric properties of the psychopathology instrument for mentally retarded adults. *Applied Research in Mental Retardation, 5,* 81-89. doi: 6721483
	Dagnan, D. & Sandhu, S. (1999). Social comparisons, self-esteem and depression in people with intellectual disability. *Journal of Intellectual Disability Research, 43,* 372-379. doi: 10.1046/j.1365-2788.1999.043005372.x
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	Catermole, M., Jahoda, A. & Markova, I. (1990). Quality of life for people with learning difficulties moving to community homes. *Disability, Handicap and Society, 5,* 137-152. doi:10.1080/02674649066780141
	Botswick, D.H. & Foss, G. (1981). Obtaining consumer input: Two strategies for identifying and ranking the problem of mentally retarded young adults. *Education and Training of the Mentally Retarded, 16,* 207-212.
	Dagnan, D., Dennia, S. & Wood, H. (1994). A pilot study of the satisfaction of people with learning disabilities with he services they receive from community psychology services. *British Journal of Developmental Disabilities, XL,* 38-44. Retrieved from http://contents.bjdd.net/oldPDFs/78_38to44.pdf
Socially reflexive questions	Szvios-Bach, S.E. (1993). Social comparisons, stigma and mainstreaming: The self-esteem of young adults with a mild mental handicap. *Mental Handicap Research, 6,* 217-236. doi: 10.1111/j.1468-3148.1993.tb00054.x
	Mateson, J.L., Kazdin, A.E., & Senatore,V. (1984). Psychometric properties of the psychopathology instrument for mentally retarded adults. *Applied Research in Mental Retardation, 5,* 81-89. doi: 6721483
	Reynolds, W.M., & Baker, J.A. (1988). Assessment of depression in persons with mental retardation. *American*

	Journal on Mental Retardation, 93, 93-103.
	Reiss, S. & Benson, B.A., Smith, D.C., & Laman, D.S (1985). Psychosocial correlates of depression in mentally retarded adults: Minimal social support and stigmatization. *American Journal of Mental Deficiency, 89,* 331-337. Retireved from http://www.ncbi.nlm.nih.gov/pubmed/4003462?dopt=Abstract
	Schalock, R.L., Keith, K.R., Hoffman, K., & Karan, O.C. (1989). Quality of life: Its measurement and use. *Mental Retardation, 27,* 25-31. Retrieved from http://www.viauc.dk/psykomotorikuddannelsen/oekonomi/Documents/QOL%20and%20IDD%20schalock%20et%20al%202002.pdf
	Kazdin, A.E., Matson, J.L., & Senatore, V., (1983). Assessment of depression in mentally retarded adults. *American Journal of Psychiatry, 140,* 1040-1043. doi: 10.1176/ajp.140.8.1040
Abstract and generalised judgements	Booth, T., & Booth, W. (1994a). The use of depth interviewing with vulnerable subjects: Lessons from a research study of parents with learning disabilities. *Social Science and Medicine, 39,* 415-424. doi:10.1016/0277-9536(94)90139-2.
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Unfamiliar content	Schalock, R.L., Keith, K.R., Hoffman, K., & Karan, O.C. (1989). Quality of life: Its measurement and use. *Mental Retardation, 27,* 25-31. Retrieved from http://www.viauc.dk/psykomotorikuddannelsen/oekonomi/Documents/QOL%20and%20IDD%20schalock%20et%20al%202002.pdf Schurr, K.T., Joiner, L.M., & Towne, R.C. (1970). Self-concept research on the mentally retarded: A review of empirical studies. *Mental Retardation, 8,* 39-43. doi: 5515365 Gowans, F & Hulberts, C. (1983). Self-concept assessment of mentally handicapped adults: A review. *Mental Handicap, 11,* 121-123. doi: 10.1111/j.1468-3156.1983.tb00145.x Nooe, R.M., (1977). Measuring self-concepts of mentally retarded adults. *Social Work, 22,* 320-322. Retrieved from http://connection.ebscohost.com/c/articles/5271422/measuring-self-concepts-mentally-retarded-adults Rapley, M. (1995). Black swans: Conversation analysis of interviews with people with learning disabilities. *Clinical Psychology Forum, 84,* 17-23. Zetlin, A.G., Heriot, M.J., & Turner, J.L. (1985). Self-concept measurement in retarded adults: A micro-analysis of responses. *Applied Research in Mental Retardation, 6,* 113-125. doi:10.1016/S0270-3092(85)80065-5 Aman, M.G. (1991). *Assessing psychopathology and behaviour problems in persons with mental retardation: a review of available instruments.* Maryland USA: National Institute of Mental Health. Moss, S., Patel, P., Prosser, H., Goldberg, D., Simpson, N, Rowe., S & Lucchino, R. (1993). Psychiatric morbidity in older people with moderate and severe learning disability: Development and reliability of the patient interview (PAS-ADD). *British Journal of Psychiatry, 163,* 359-367. doi: 10.1192/bjp.163.4.471 Moss, S., Prosser, H., & Goldberg, D. (1996). Validity of the schizophrenia diagnosis of the psychiatric assessment

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	Castles, E.E. & Glass, C.R., (1986). Training in social and interpersonal problem solving skills for mildly and moderately mentally retarded adults. *American Journal of Mental Deficiency, 91,* 35-42. Retrieved from: http://www.ncbi.nlm.nih.gov/pubmed/3740114
	Nooe, R.M., (1977). Measuring self-concepts of mentally retarded adults. *Social Work, 22,* 320-322. Retrieved from http://connection.ebscohost.com/c/articles/5271422/measuring-self-concepts-mentally-retarded-adults
Sensitive content	Barnett, J. (1998). Sensitive questions and response effects: An evaluation. *Journal of Managerial Psychology, 13,* 63-76. doi 10.1108/02683949810369138
	Biklen, S.K., & Moseley, C.R., (1988). Are you retarded? No I'm Catholic: Qualitative methods in the study of people with severe handicaps. *Journal for the Association of People with Severe Handicaps, 13,* 155-162.
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	Pack, R.P., Wallander., J.L, & Browne, D. (1998). Health risk behaviours of African American adolescents with mild mental retardation; Prevalence depends on measurement method. *American Journal of Mental Retardation,*

	102, 409-420. doi: http://dx.doi.org/10.1352/0047-6765(2006)44[212:IPACAA]2.0.CO;2
Question Phrasing	Kabzems, V. (1985). The use of self-report measures with mentally retarded individuals. *Mental Retardation and Learning Disability Bulletin, 13,* 106-114. Retrieved from: http://psycnet.apa.org/psycinfo/1986-20543-001
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	Prosser, H., Bromley, J., (1998). Interviewing people with intellectual disabilities. In Emerson, C., Hatton, J., Bromley, J., & A. Caine. (Eds). *Clinical Psychology and people with intellectual disabilities.* Chichester: Wiley.
	Wyngaarden, M. (1981). Interviewing mentally retarded persons: Issues and strategies. In R.H. Bruininks, C.E., Meyers, B.B., Sigford, & K.C. Lakin (Eds). *Deinstitutionalization and community adjustment of mentally retarded people.* Washington DC: American Association of Mental Deficiency.
	Matson, J.L. & Frame, C.L. (1986). *Psychopathology among mentally retarded children and adolescents.* California: SAGE.
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Negatively worded questions and modifiers	Gough, P.B.(1965). Grammatical transformations and speed of understanding. *Journal of Verbal Learning and Verbal Behaviour, 4,* 107-111. doi:10.1016/S0022-5371(65)80093-7
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	Lowe, K., & de Paiva, S. (1988). Canvassing the views of people with a mental handicap. *Irish Journal of Psychology, 9*, 220-234. doi:10.1080/03033910.1988.10557718
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	Eysenck, S.B.G. (1965). *Manual of the Eysenck-Withers Personality Inventory for subnormal subjects.* London: University of London Press.
	Szvios-Bach, S.E. (1993). Social comparisons, stigma and mainstreaming: The self-esteem of young adults with a mild mental handicap. *Mental Handicap Research, 6,* 217-236. doi: 10.1111/j.1468-3148.1993.tb00054.x
Subject-object confusion and passive phrasing	Slobin, D.I. (1966). Grammatical transformations and sentence comprehension in childhood and adulthood. *Journal of Verbal Learning and Verbal Behaviour, 5,* 219-227. doi:10.1016/S0022-5371(66)80023-3
	Gough, P.B.(1965). Grammatical transformations and speed of understanding. *Journal of Verbal Learning and Verbal Behaviour, 4,* 107-111. doi:10.1016/S0022-5371(65)80093-7
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	Mateson, J.L., Kazdin, A.E., & Senatore,V. (1984). Psychometric properties of the psychopathology instrument for mentally retarded adults. *Applied Research in Mental Retardation, 5,* 81-89. doi: 6721483
Giving examples	Sigelman, C.K., Shoenenrock, C.J., Winer, J.L., Spanhel, C.L., Hromes, S.G., Martin, R.W., Budd, E.C., & Bensberg, G.J. (1981). Issues in interviewing mentally retarded persons: An empirical study. In R.H. Bruninks, C.E. Meyers, B.B., Sigford, & K.C. Lakin (Eds). *Deinstitutionalization and community adjustment of mentally*

	retarded people. Washington DC: American Association of Mental Deficiency.
Yes/No questions and acquiescence	Block, J. (1965). *The challenge of response sets.* New York: Appleton-Century-Crofts.
	Kebbell, M.R., & Hatton, C. (1999). People with mental retardation as witnesses in court: A review. *Mental Retardation, 37,* 179-187. doi: 10.1352/0047-6765.
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	Sigelman, C.K., Shoenenrock, C.J., Winer, J.L., Spanhel, C.L., Hromes, S.G., Martin, R.W., Budd, E.C., & Bensberg, G.J. (1981). Issues in interviewing mentally retarded persons: An empirical study. In R.H. Bruninks, C.E. Meyers, B.B., Sigford, & K.C. Lakin (Eds). *Deinstitutionalization and community adjustment of mentally retarded people.* Washington DC: American Association of Mental Deficiency.
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Appendix 13: Results From Literature Search and Thematic Analysis

*Table of themes for the measure redevelopment**

Difficulty identified	Change made to AQ-10
Readability Length: participants felt longer words and sentences were more difficult to understand	The sentences should have an approximate Flesch Reading Score of above 70 (Flesch, 1949). • Only commonly used words were used when revising
Unfamiliar content The thematic analysis revealed that participants struggled with words they had not heard before	• Original pictures were designed and used to aid understanding. Although participants commented that they would like these to be in colour, only black and white was used. This is because many NHS organisations print questionnaires solely in black and white. • The pictures themselves were simple and gender free to allow for them to be generalised.
Question Content • Questions that ask about judgements of frequency or degree have been found to be problematic. • Socially reflexive questions have been identified as being	• Question 4 of the AQ-10 reworded to not include the subjective judgement of "quickly". • Question 1 reworded so the participant does not have to compare themselves to others to be able to answer

difficult for many people • Difficulties have been found with generalizing questions • Abstract concepts such as question 5 are difficult for people with leaning disabilities	• The examiner crib also encourages the examiner to check the meaning of the answers given • Question 8 reworded to make the question more general to hobbies rather than being interpreted as specific the examples given • Examiner crib sheet used to help examiner elaborate • Question 5 and 10 changed to be more specific in using a concrete example
Interpretations The thematic analysis also revealed that many of the participants found the use of metaphor in the measure difficult with some interpreting the wording literally.	• Question 5 changed to avoid the use of metaphor • Question 2 reworded to avoid metaphor. Alternative questions provided in the examiner crib sheet.
Insight Research suggests that individuals with learning disabilities and ASD have difficulties with self-insight, suggesting difficulties with answering questions that ask them to judge themselves (their abilities for example)	• Question 9, question 6, question 5 and question 3 modified to take out the phrase "I find it easy" and use more concrete examples. The examiner crib provides probe questions.
Question Phrasing Question phrasing can be difficult for some individuals with learning	• All questions reworded to ask "do you" instead of asking participants to agree / disagree with "I" statements

disabilities. Some participants had difficulties understanding who the subject was in the questions, i.e. they did not understand whether "I" referred to them or to the examiner

Response format

- Likert Scale - The thematic analysis revealed many found the nature of the Likert scale too difficult to use. Many found it required too much abstraction, when combined with "I" questions.
- Participants revealed that if they did not know the answer, they would guess, as there was not a ‘don't know’ option, leaving responses to be inaccurate.
- Acquiescence has been shown to be more problematic in gaining information from people with learning disabilities.

Layout

- Participants commented that they found the scoring information at the bottom distracting and confusing.
- Yes/No' responses instead of 4-point Likert scale.
- A don't know option was added.
- An examiner crib sheet was designed so examiners could probe further or ask follow up questions.
- Question 8 changed to make it more open ended regarding their hobby. The examiner crib then helps the examiner to assess whether the hobby could be classed as a RRBI. A follow up question asking about frequency also helps the examiner judge the degree to which it might be an RRBI
- The use of the 'don't know' option reduces acquiescence as well as the use of the examiner crib to allow the examiner to take more of a semi-structured approach if they feel that the individual might be acquiescing.
- The revised measure scoring instructions can be hidden by folding along the fold line to avoid distraction.
- Information regarding where to start and stop in given so the

• One participant commented that they want a place to put their name on the form	participants knows the scoring information section does not need to be filled in by them • A place for their name was included at the top of the revised measure. An option to fill in the date of testing at the bottom is provided for the examiner should the measure need to be repeated another time.
Support Some participants reported that they would need help to fill the questionnaire in, even with modifications suggesting that there are difficulties with making the measure inclusive of all levels of ability.	• The examiner crib allows the AQ-10-R to be administered using a semi-structured interview format rather than a self-report tool if needed.

*****_For a list of the references used in determining the difficulties of using self-report measures with people with learning disabilities, as collated via themes in this table, refer to appendix 12._

Appendix 14: AQ-10-R

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Appendix 15: Examiner crib

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Appendix 16: The AQ-10

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Appendix 17: Sample transcript

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Appendix 18: Feedback to NHS and university Ethics Committees

Using the AQ-10 Questionnaire with Adults who have a borderline OR Mild Learning Disability: A Measure Redesign

Background and Rationale

The aim of this study was to explore the use of the AQ-10 questionnaire (Allison, Auyeung & Baron-Cohen, 2012) with adults who have a borderline or mild learning disability.

Autism Spectrum Disorder (ASD) affects many people in the UK and can have a significant impact on one's well-being. Many people who have ASD also have a learning disability. In recent times, researchers, clinicians and commissioners alike have began to explore the best way to identify (or screen) and diagnose ASD in adults and as a result of this, referral guidelines have been put in place.

Within these guidelines there was a recognition that identifying ASD is difficult and requires specialist knowledge; something which front-line clinicians do not always have the time or training for. Therefore, the guidelines suggested the use of a case identification questionnaire (or screening tool) that clinicians could use to help them in making decisions regarding whether to refer the service-user for a full diagnostic assessment.

The screening tool of choice identified was the AQ-10; a ten-item self-report questionnaire aimed to screen for ASD symptomatology in adults. It was suggest that this questionnaire could be used with people with no learning disabilities, as well as those with borderline or mild learning disabilities. However, this questionnaire was not developed or validated on those with IQs that would place them in the borderline or mild range and so the appropriateness of this tool for this population is unknown.

The aim of this study was to explore whether the AQ-10 makes a good screening tool for those with a borderline or mild learning disability. Specifically, the project aimed to explore how adults with a borderline or mild learning disability experience using the AQ-10 in its current form in order to investigate whether it can be adequately understood by service-users and evidences valid responses. Based on these findings, the study then aimed to redesign the measure in consultation with service-users and then pilot it on a group of adults with borderline or mild learning disabilities to examine some early psychometric properties of the revised measure.

The Findings

A number of findings emerged from the study. Firstly, findings from the focus group of adults suggest that the AQ-10 in its original form is difficult to use and understand without adaptations to the administration. The main of areas of difficulty identified by the experts by experience centred on themes of the readability level required being too high, the layout (such as the scaling system) being too hard to use, difficulties in understanding the metaphor in the questionnaire and difficulty in having to make subjective estimations. Themes also emerged of the experts making guesses, acquiescing and relying on help or visual cues in order to help them fill in the measure. Participants also described certain emotions being connected with using the measure, such as anxiety or fear.

As a result of these findings, the experts identified a number of ways in which the measure could be redesigned. These ideas included making changes to include pictures, changing the scale, making the language more simple and reducing ambiguity. A systematic literature search was also carried out to identify further ways

in which the measure could be revised to make it more accessible for those with borderline or mild learning disabilities.

Following the redesign, the revised measure (AQ-10-R) was piloted on a small sample of adults with borderline or mild learning disabilities. The results revealed the revised measure to have good diagnostic validity, sensitivity and specificity. On the other hand, the AQ-10 in its current form showed poor diagnostic validity for this population.

These findings suggest that without revision, the AQ-10 may not diagnostically valid for those with mild or borderline learning disabilities. However, with simple revision, such as changing the layout, providing clinicians with prompt questions and reducing the complexity of the words, the AQ-10 could be used as a case-identification tool for those with mild or borderline learning disabilities.

Conclusions and Recommendations

Many Trusts are now recognising that ASD remains a lifelong condition and with the recent revisions to the diagnostic criteria, it is timely that consideration be paid to case identification and diagnostic procedures for ASD.

The current results suggest that more attention is needed to the issue of case identification, in particular in those with ASD *and* a learning disability. Clarification is needed to establish the appropriate screening methods for the spectrum of learning disability, rather than using one-size fits all approach. Guidelines and research alike need to recognise the impact of learning disability when screening for ASD symptomatology in adults.

Using the AQ-10 Questionnaire with Adults who have a borderline OR Mild Learning Disability: A Measure Redesign

Earlier this year, you took part in some research. I would like to tell you the results of this research.

You will remember, I asked you to fill in **two** questionnaires about Autism.

One questionnaire was in **'easy-read**' format. The other questionnaire was not. **You filled in both** to see if one was **better** than the other.

We found out that people with mild **learning disabilities** found the **easy-read** questionnaire **easier** to use than the not easy-read questionnaire.

This is an **important** finding because it shows how important it is to **make**

questionnaires easy so all people can use them.

With **simple changes**, like making the words **shorter** and using **pictures**, the questionnaire became easier to understand and this meant that it could be filled in **without needing too much help from others.**

We hope that research was interesting for you. We would like to thank you very much for giving your time to take part. If you have any questions, or would like to talk about the results more, please contact me on the details below.

Best wishes,

Lizzie Kent

l.c.kent153@canterbury.ac.uk

Canterbury Christ Church University

Appendix 19: Publication guidelines for Journal of choice.

Journal of Autism and Developmental Disorders

- All JADD manuscripts should be submitted to Editorial Manager in 12-point Times New Roman with standard 1-inch borders around the margins.
- APA Style
- Text must be double-spaced; APA Publication Manual standards must be followed.
- As of January 20, 2011, the Journal has moved to a double-blind review process. Therefore, when submitting a new manuscript, DO NOT include any of your personal information (e.g., name, affiliation) anywhere within the manuscript. When you are ready to submit a manuscript to JADD, please be sure to upload these 3 separate files to the Editorial Manager site to ensure timely processing and review of your paper:
    - A title page with the running head, manuscript title, and complete author information. Followed by (page break) the Abstract page with keywords and the corresponding author e-mail information.
    - The blinded manuscript containing no author information (no name, no affiliation, and so forth).

Articles, Brief Reports, Letters to the Editor, Commentaries

- The preferred article length is 20-23 double-spaced manuscript pages long (not including title page, abstract, tables, figures, addendums, etc.) Manuscripts of 40 double-spaced pages (references, tables and figures counted as pages) have been published. The reviewers or the editor for your review will advise you if a longer submission must be shortened.
- Special Issue Article: The Guest Editor may dictate the article length; maximum pages allowed will be based on the issue's page allotment.
- A Brief Report: About 8 double-spaced pages with shorter references and fewer tables/figures. May not meet the demands of scientific rigor required of a JADD article – can be preliminary findings.
- A Letter to the Editor is 6 or less double spaced pages with shorter references, tables and figures. Style sheet for Letter to the Editor:
- A title page with the running head, manuscript title, and complete author

information including corresponding author e-mail information

- The blinded manuscript containing no author information (no name, no affiliation, and so forth):- - 6 or less double spaced pages with shorter references, tables and figures - Line 1: “Letter to the Editor” - Line 3: begin title (note: for “Case Reports start with “Case Report: Title”) - Line 6: Text begins; references and tables, figure caption sheet, and figures may follow (page break between each and see format rules)
- Title Page with all Author Contact Information & Abstract with keywords and the corresponding author e-mail information.

Manuscript Submission

- Submission of a manuscript implies: that the work described has not been published before; that it is not under consideration for publication anywhere else; that its publication has been approved by all co-authors, if any, as well as by the responsible authorities – tacitly or explicitly – at the institute where the work has been carried out. The publisher will not be held legally responsible should there be any claims for compensation.

Permissions

- Authors wishing to include figures, tables, or text passages that have already been published elsewhere are required to obtain permission from the copyright owner(s) for both the print and online format and to include evidence that such permission has been granted when submitting their papers. Any material received without such evidence will be assumed to originate from the authors.

Online Submission

- Authors should submit their manuscripts online. Electronic submission substantially reduces the editorial processing and reviewing times and shortens overall publication times. Please follow the hyperlink “Submit online” on the right and upload all of your manuscript files following the instructions given on the screen.

The title page should include:

- The name(s) of the author(s)
- A concise and informative title
- The affiliation(s) and address(es) of the author(s)
- The e-mail address, telephone and fax numbers of the corresponding author

Please provide an abstract of 120 words or less. The abstract should not contain any undefined abbreviations or unspecified references.

Please provide 4 to 6 keywords which can be used for indexing purposes.

Text Formatting

- Manuscripts should be submitted in Word.
- Use a normal, plain font (e.g., 10-point Times Roman) for text.
- Use italics for emphasis.
- Use the automatic page numbering function to number the pages.
- Do not use field functions.
- Use tab stops or other commands for indents, not the space bar.
- Use the table function, not spreadsheets, to make tables.
- Use the equation editor or MathType for equations.
- Save your file in docx format (Word 2007 or higher) or doc format (older Word versions).

Headings

Please use no more than three levels of displayed headings.

Abbreviations

Abbreviations should be defined at first mention and used consistently thereafter.

Footnotes

- Footnotes can be used to give additional information, which may include the citation of a reference included in the reference list. They should not consist solely of a reference citation, and they should never include the bibliographic details of a reference. They should also not contain any figures or tables.

- Footnotes to the text are numbered consecutively; those to tables should be indicated by superscript lower-case letters (or asterisks for significance values and other statistical data). Footnotes to the title or the authors of the article are not given reference symbols.
- Always use footnotes instead of endnotes.

Acknowledgments

- Acknowledgments of people, grants, funds, etc. should be placed in a separate section before the reference list. The names of funding organizations should be written in full.
- The body of the manuscript should begin on a separate page. The manuscript page header (if used) and page number should appear in the upper right corner. Type the title of the paper centered at the top of the page, add a hard return, and then begin the text using the format noted above. The body should contain:

. Introduction (The introduction has no label.)

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. Results (Center the heading.)

. Discussion (Center the heading.)

Please use no more than three levels of displayed headings.

- Level 1: Centered
- Level 2: Centered Italicized
- Level 3: Flush left, Italicized
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The first paragraph contains a separate phrase for each author’s name and the affiliations of the authors at the time of the study (include region and country).

The second paragraph identifies any changes in the author affiliation subsequent to the time of the study and includes region and country (wording: “authors name is now at affiliation”.)

The third paragraph is Acknowledgments. It identifies grants or other financial support and the source, if appropriate. It is also the place to acknowledge colleagues who assisted in the study and to mention any special circumstances such as the presentation of a version of the paper at a meeting, or its preparation from a doctoral dissertation, or the fact that it is based on an earlier study.

The fourth paragraph states, “Correspondence concerning this article should be addressed to…” and includes the full address, telephone number and email address of the corresponding author.

Please always use internationally accepted signs and symbols for units (SI units). Generic names of drugs and pesticides are preferred; if trade names are used, the generic name should be given at first mention.

Please use the standard mathematical notation for formulae, symbols etc.: Italic for single letters that denote mathematical constants, variables, and unknown quantities Roman/upright for numerals, operators, and punctuation, and commonly defined functions or abbreviations, e.g., cos, det, e or exp, lim, log, max, min, sin, tan, d (for derivative) Bold for vectors, tensors, and matrices.

Citation

- Cite references in the text by name and year in parentheses. Some examples: Negotiation research spans many disciplines (Thompson 1990).

. This result was later contradicted by Becker and Seligman (1996).

. This effect has been widely studied (Abbott 1991; Barakat et al. 1995; Kelso and Smith 1998; Medvec et al. 1999).

Reference list

- The list of references should only include works that are cited in the text and that have been published or accepted for publication. Personal communications and unpublished works should only be mentioned in the text. Do not use footnotes or endnotes as a substitute for a reference list.
- Reference list entries should be alphabetized by the last names of the first author of each work.

. Journal article Harris, M., Karper, E., Stacks, G., Hoffman, D., DeNiro, R., Cruz, P., et al. (2001). Writing labs and the Hollywood connection. Journal of Film Writing, 44(3), 213–245.

. Article by doi Slifka, M. K., & Whitton, J. L. (2000) Clinical implications of dysregulated cytokine production. Journal of Molecular Medicine, doi:10.1007/s001090000086

. Book Calfee, R. C., & Valencia, R. R. (1991). APA guide to preparing manuscripts for journal publication. Washington, DC: American Psychological Association.

. Book chapter O'Neil, J. M., & Egan, J. (1992). Men's and women's gender role journeys: Metaphor for healing, transition, and transformation. In B. R. Wainrib (Ed.), Gender issues across the life cycle (pp. 107–123). New York: Springer.

. Online document Abou-Allaban, Y., Dell, M. L., Greenberg, W., Lomax, J., Peteet, J., Torres, M., & Cowell, V. (2006). Religious/spiritual commitments and psychiatric practice. Resource document. American Psychiatric Association. http://www.psych.org/edu/other_res/lib_archives/archives/200604.pdf. Accessed 25 June 2007.

- Journal names and book titles should be italicized.
- For authors using EndNote, Springer provides an output style that supports the formatting of in-text citations and reference list.

EndNote style (zip, 3 kB)

- All tables are to be numbered using Arabic numerals.

- Tables should always be cited in text in consecutive numerical order.
- For each table, please supply a table caption (title) explaining the components of the table.
- Identify any previously published material by giving the original source in the form of a reference at the end of the table caption.
- Footnotes to tables should be indicated by superscript lower-case letters (or asterisks for significance values and other statistical data) and included beneath the table body.
- Each table should be inserted on a separate page at the back of the manuscript in the order noted above. A call-out for the correct placement of each table should be included in brackets within the text immediately after the phrase in which it is first mentioned. Copyright permission footnotes for tables are typed as a table note.

Electronic Figure Submission

- Supply all figures electronically.
- Indicate what graphics program was used to create the artwork.
- For vector graphics, the preferred format is EPS; for halftones, please use TIFF format. MSOffice files are also acceptable.
- Vector graphics containing fonts must have the fonts embedded in the files.
- Name your figure files with "Fig" and the figure number, e.g., Fig1.eps.

.

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Color art is free of charge for online publication.

If black and white will be shown in the print version, make sure that the main information will still be visible. Many colors are not distinguishable from one another when converted to black and white. A simple way to check this is to make a xerographic copy to see if the necessary distinctions between the different colors are still apparent.

If the figures will be printed in black and white, do not refer to color in the captions.

Color illustrations should be submitted as RGB (8 bits per channel).

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Variance of type size within an illustration should be minimal, e.g., do not use 8-pt type on an axis and 20-pt type for the axis label.

Avoid effects such as shading, outline letters, etc.

Do not include titles or captions within your illustrations.

Figure Numbering

All figures are to be numbered using Arabic numerals.

Figures should always be cited in text in consecutive numerical order.

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If an appendix appears in your article and it contains one or more figures, continue the consecutive numbering of the main text. Do not number the appendix figures, "A1, A2, A3, etc." Figures in online appendices (Electronic Supplementary Material) should, however, be numbered separately.

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Figure captions begin with the term Fig. in bold type, followed by the figure number, also in bold type.

No punctuation is to be included after the number, nor is any punctuation to be placed at the end of the caption.

Identify all elements found in the figure in the figure caption; and use boxes, circles, etc., as coordinate points in graphs.

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Refer to the supplementary files as “Online Resource”, e.g., "... as shown in the animation (Online Resource 3)", “... additional data are given in Online Resource 4”.

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Accessibility

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Appendix 19: Semi-structured Questions for Focus Group

1. How did you find filling out the AQ-10
2. What was the biggest difficulty you experienced?
3. Were there any good aspects of the questionnaire?
4. What do you think about the layout?
5. What do you think about the “agree, disagree” categories?
6. Do you understand the language?
7. What do you think about including pictures instead of words?
8. What other changes to you think need to be made to make it better and more understandable?