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Screening for intellectual disability in autistic people: A brief report

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ABSTRACT

Background: There is high co-occurrence between intellectual disability and Autism Spectrum Disorder (ASD). It is important to identify people who have both conditions for clinical and research reasons. This study explored if the Child and Adolescent Intellectual Disability Screening Questionnaire (CAIDS-Q) and Learning Disability Screening Questionnaire (LDSQ) could accurately identify intellectual disability in autistic children and adults respectively.
Method: Pre-existing CAIDS-Q data for 40 autistic children and LDSQ data for 27 autistic adults were used. The participants were classified as likely to have an intellectual disability or not based on the age-appropriate cut-off score on the relevant screening tools. This was compared with their clinical diagnosis of intellectual disability.
Results: The sensitivity, specificity, and positive and negative predictive values, for the CAIDS-Q were 93.1 %, 88.5 %, 90 % and 92 % respectively. The corresponding figures for the LDSQ were 75 %, 95.6 %, 75 %, and 95.6 %.
Conclusions: The values for the CAIDS-Q were broadly consistent with figures found in previous research. The sensitivity and PPV figures for the LDSQ, were somewhat lower. The specificity and sensitivity values for both measures were above the threshold for levels that are generally considered to be acceptable for a developmental screening tool. The results suggest that the CAIDS-Q and LDSQ may be appropriate measures to screen for intellectual disability in autistic people.

1. Introduction

There is a high rate of co-occurrence of Autism Spectrum Disorder (ASD) and intellectual disability, with research indicating that approximately 40–70 % of autistic people also have an intellectual disability (Buescher et al., 2014; Matson & Shoemaker, 2009). While each condition has its own distinct diagnostic criteria, there are areas of overlap in both the aetiology and behavioural characteristics, which can make differential diagnosis challenging (Thurm et al., 2019). For example, restricted and stereotyped behaviours form part of the diagnostic criteria for ASD (American Psychiatric Association, 2013), but are also displayed by many people with an intellectual disability (e.g., National Institute for Health & Care Excellence NICE, 2015). There is also considerable overlap in the suggested indicators of ASD (Scottish Intercollegiate Guidelines Network SIGN, 2016), such as difficulties with communication, social relationships, and employment, with many people with an intellectual disability also experiencing challenges in these areas (e.g.,

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Retznik et al., 2022; Smith et al., 2020; Taubner et al., 2021).

It is important to identify individuals who have either or both conditions for clinical, theoretical, and research purposes (Thurm et al., 2019). In terms of clinical aspects, as people with an intellectual disability, by definition, have significant difficulties with their adaptive and intellectual functioning (American Psychiatric Association, 2013), autistic individuals who also have an intellectual disability are likely to have somewhat differing needs and experiences in relation to diagnostic assessment (McKenzie, Forsyth et al., 2015) and support needs (Shogren et al., 2017) from those with ASD or intellectual disability alone. The groups may also differ in terms of their clinical outcomes, with research suggesting that autistic people with an intellectual disability may have poorer outcomes compared with those without an intellectual disability (see Scottish Intercollegiate Guidelines Network SIGN, 2016). Identifying those who fall within the former group is, therefore, important to ensure that their needs are met appropriately.

Theoretical advances in the understanding of, and interventions for, ASD and intellectual disability can only occur if those who have either distinct or co-occurring conditions are included in research. Thurm et al. (2019) report, however, that people with an intellectual disability are increasingly less likely to be included in ASD research. One reason for this may be because the diagnosis of both intellectual disability (Winters et al., 2005) and ASD (McKenzie, Forsyth et al., 2015) can require a significant amount of time and effort, both on the part of the individual and diagnosing professionals. Clinical researchers may not have the time, resources, or qualifications to undertake full diagnostic assessment for intellectual disability and/or ASD for every potential or actual participant and so may need an alternative way to group participants according to likelihood of having a particular condition (Spinks et al., 2009).

Screening questionnaires, while not substitutes for full diagnostic assessment, can offer one way of helping to identify those who are most likely to have an intellectual disability and/or ASD for clinical or research purposes. Indeed, one of the Scottish Intercollegiate Guidelines Network SIGN (2016) recommendations was to conduct 'studies into the adaptation and/or development of identification and screening tools for children and adults with ASD who have an intellectual disability.' (p51).

It is important that screening tools have robust psychometric properties to help minimise the misclassification of people and to ensure that users can be confident in their results (Glascoe, 2005; Trevethan, 2017). Two important indicators of the quality of any screening tool are sensitivity and specificity. These refer to the extent to which it correctly identifies the proportion of people with and without the condition respectively, based a comparison with a 'gold' or 'reference' standard (Trevethan, 2017). When considering the performance of the screening tool in practice, positive and negative predictive values are important to consider. Positive predictive value (PPV) reflects the likelihood that those who are indicated on the screening tool as having the condition, do actually have it. Similarly, negative predictive value (NPV) reflects the likelihood that those who are indicated on the screening tool as not having the condition, do not actually have it.

The characteristics of any screening tool are affected by how common the condition is in the population that is being screened (Power et al., 2013). Likewise, the desired balance between sensitivity and specificity of a screening tool is influenced by the purpose of the tool and the contexts within which it will be used. It has, however, been recommended that acceptable sensitivity and specificity values for screening for developmental disabilities should be higher than 70 % and 80 % respectively (American Academy of Pediatrics, 2001; Glascoe, 2005). Similarly, decisions about target PPV and NPV values can be influenced by considerations of the potential impact on the individual and wider system of a test over-or under-identifying people with the target condition (Trevethan, 2017). There is limited guidance on acceptable levels of PPV and NPV demonstrated by tools that aim to screen for developmental disability, however, Glascoe (2005) notes that PPV may commonly range between 30 % and 50 % in practice.

Screening for co-occurring intellectual disability and ASD can take place by screening those with known ASD for intellectual disability, screening those with known intellectual disability for ASD or screening for both conditions in populations where diagnostic status is unknown. All of these options rely on having screening tools that are accurate when used with people with intellectual disability and ASD. A number of screening tools for ASD exist, but there is limited evidence that they have robust psychometric properties when used to screen for ASD in people with an intellectual disability (Metcalfe et al., 2020).

There are fewer screening questionnaires for intellectual disability available. While abbreviated and short-forms of intellectual assessments have been used for this purpose (e.g. Hayes, 2002; Paxton et al., 2008), these have some limitations. They usually only measure one of the criteria for intellectual disability, most commonly cognitive functioning, they usually require the user to have a specific professional background and/or qualification which can limit their use, they often need to be completed directly with the person concerned, and they have not generally been specifically standardised and evaluated for use with people with an intellectual disability.

Two screening tools that address these difficulties are the Child and Adolescent Intellectual Disability Screening Questionnaire (CAIDS-Q: McKenzie et al., 2012) and the adult version, the Learning Disability Screening Questionnaire (LDSQ: McKenzie & Paxton, 2006). These have both demonstrated good psychometric properties in a variety of clinical settings and other populations (see McKenzie et al., 2021 for an overview) and have been found to have comparable performances to short-form intellectual assessments, while taking less time to administer (McKenzie et al., 2014; Paxton et al., 2008).

The CAIDS-Q has recently been highlighted by the National Autism Implementation Team as an example of information gathering tools to support clinical decision making (Rutherford et al., 2021). To the authors' knowledge, however, no previous research has explored their use specifically with autistic people. The present study, therefore, aimed to evaluate the sensitivity, specificity, PPV and NPV of the CAIDS-Q and LDSQ when used to screen for intellectual disability in autistic people. When used with people with a known diagnosis of ASD, sensitivity values would indicate the ability of the tools to identify co-occurrence of ASD and intellectual disability. Specificity values would indicate the ability of the tools to differentiate between the two i.e., autistic people who were not likely to meet the criteria for intellectual disability.

2. Methods

2.1. Participants

CAIDS-Q and LDSQ data were drawn from previous larger studies, therefore the participants were not specifically recruited for the present study. The sample was chosen on the basis that the person concerned had a diagnosis of autism and had associated CAIDS-Q data (for children) or LDSQ data (for adults).

CAIDS-Q data for 55 autistic children/young people was included in the study. Their ages ranged between 6 years and 17 years, 8 months ($M = 11.1$ years, $SD = 2.9$) Thirteen (24.1 %) were female and 41 (75.9 %) were male. Data was missing for one person. Twenty-nine (52.7 %) had a clinical diagnosis of intellectual disability.

LDSQ data for 27 autistic adults was also included. Their ages ranged between 18 and 55 years ($M = 32$, $SD = 10.8$). Thirteen (48.1 %) were males, 12 (44.4 %) were female, and 2 (7.4 %) recorded themselves as 'other.' Four (14.8 %) had a clinical diagnosis of intellectual disability.

3. Materials & design

Child and Adolescent Intellectual Disability Screening Questionnaire (CAIDS-Q: McKenzie et al., 2012). The CAIDS-Q is a short, seven item questionnaire for children and young people aged between 6 and 18 years. It comprises questions relating to literacy, self-care skills, friendships, and support needs. A percentage total score is calculated, and an age-appropriate cut-off score is used to indicate whether the person is likely to meet the criteria for intellectual disability or not.

The CAIDS-Q has been used in a range of clinical and forensic settings and has been found to have good psychometric properties (see McKenzie et al., 2020 for an overview). Recent research conducted in paediatric settings reported sensitivity and NPV of 100 %. Specificity values ranged between 83 % and 94 %, and PPV ranged between 75 % and 88 %, depending on the age of the child (McKenzie et al., 2019).

Learning Disability Screening Questionnaire (LDSQ: McKenzie & Paxton, 2006). The LDSQ is also a seven-item questionnaire designed for people aged 16 years and older. Those with a percentage score that falls below the relevant cut-off are indicated as likely to meet the criteria for intellectual disability. Like the CAIDS-Q, the LDSQ has also been used in different settings and found to demonstrate good psychometric properties (see McKenzie et al., 2021). A study which validated the LDSQ against the updated Weschler Adult Intelligence Scale (Wechsler, 2010) found it to have sensitivity and specificity values of 91.5 % and 91.7 % respectively. PPV and NPV can be calculated from the reported figures and were 96.5 % and 84.6 % respectively (McKenzie & Sharples, 2015).

Online versions of both screening tools can be found at https://learningdisabilitymatters.co.uk/tools/.

The study used an observational design, using anonymous, pre-existing data that had been gathered during the course of previous research. All of these previous projects had obtained ethical and/or Caldicott Guardian approval from the relevant NHS or University body. Participant and in the case of those aged under 18, parental/guardian informed consent was obtained where appropriate. The data were based on informant reports.

3.1. Procedures

Pre-existing, anonymous data gathered as part of previous studies were used for the study. Only data for those who had a diagnosis of ASD were included. In relation to diagnosis for intellectual disability, in addition to a developmental history, intellectual functioning was most commonly assessed by using the age-appropriate version of the Wechsler Intelligence scales. Adaptive functioning was assessed using standardised scales, such as the Vineland Adaptive Behaviour Scales (Sparrow et al., 2016) or the Adaptive Behaviour Assessment System (Harrison & Oakland, 2015). The specific assessments used for the diagnosis of ASD were unknown, as these diagnoses were not carried out by the researchers. In all cases, however, diagnosis of intellectual disability and/or ASD was recorded based on the outcome of an assessment by a health or educational professional or multi-disciplinary team based in the United Kingdom.

3.2. Analysis

The participants were classified as likely to meet the criteria for intellectual disability or not based on the relevant cut-off score on

Table 1
The status of participants in relation to intellectual disability, based on clinical diagnosis, CAIDS-Q, and LDSQ scores.

Intellectual disability		Clinical diagnosis	
		Yes	**No**
CAIDS-Q status (Child Subsample)	**Yes**	27	3
	No	2	23
		Yes	**No**
LDSQ status (Adult subsample)	**Yes**	3	1
	No	1	22

the CAIDS-Q or LDSQ, according to their age. Sensitivity, specificity, positive and negative predictive values were calculated, using the formula outlined by Trevethan (2017).

4. Results

Table 1 shows the status of participants in relation to intellectual disability, based on clinical diagnosis, CAIDS-Q Scores for the child subsample and LDSQ scores for the adult subsample.

Table 2 illustrates the sensitivity, specificity, positive and negative predictive values, for the CAIDS-Q, based on the child subsample, and LDSQ, based on the adult subsample.

5. Discussion

This study aimed to explore some of the psychometric properties of the CAIDS-Q, as completed for a child sample, and LDSQ, as completed for an adult sample, to see if they could be useful in identifying autistic people who were also likely to meet the criteria for intellectual disability. Overall, 52.7 % of the children had a diagnosed intellectual disability. This figure is broadly consistent with lower end estimates from previous research that has indicated that between 40 % and 70 % of autistic people also have an intellectual disability (Buescher et al., 2014; Matson & Shoemaker, 2009).

Only four of the adults (14.8 %) had a diagnosis of intellectual disability, which is lower than previous research suggests. This discrepancy may be because the adult participants had to provide informed consent in the original studies from which the data were drawn, which excluded those with more severe levels of intellectual disability. The adult sample, does, however, reflect those whose intellectual disability would be more difficult to identify, as research suggests that the majority of adults with a mild intellectual disability do not have their condition recognised by services (Emerson & Glover, 2012).

The study found values for the CAIDS-Q that were broadly consistent with the figures found in recent research in paediatric services (McKenzie et al., 2019). The sensitivity figure and NPV were slightly lower, but both were still above 90 %. The PPV in the present study was higher at 90 % and the specificity value, at 88.5 % fell within the range found in the study by McKenzie and colleagues. Both the specificity and sensitivity values are also above the threshold for levels that are considered acceptable for a screening tool (e.g., Glascoe, 2005).

The sensitivity and PPV figures for the LDSQ, at 75 %, were lower than those found in the 2015 study by McKenzie et al. The sensitivity value was, however, greater than the 70 % threshold recommended for an acceptable developmental screening tool (American Academy of Pediatrics, 2001; Glascoe, 2005). Likewise, the PPV was much higher than the 30–50 % range that Glascoe (2005) notes is commonly found for developmental assessments. Both the specificity and NPV values were above 95 % and were higher than those found in the study by McKenzie and Sharples (2015).

6. Implications

The results have implications for practice. It is important to have evidence-based and accurate intellectual disability screening measures, particularly when co-occurrence with ASD may make identification of the condition more difficult. Research indicates that using less formal methods to identify likely intellectual disability can be inaccurate. For example, estimates of intelligence by parents, others, and self can be significantly influenced by factors other than actual cognitive ability, such as gender, culture, and educational background (e.g., Bian et al., 2017; Kirkcaldy et al., 2007; Swami et al., 2009). In addition, knowledge of intellectual disability is low in many staff groups (e.g., Emerson, Baines et al., 2012; McKenzie et al., 2022), suggesting that they may be poor at identifying indicators of intellectual disability. Using more formal measures, such as abbreviated or short forms of intellectual assessments, which have not specifically been designed as intellectual disability screening tools, can also have limitations, as outlined in the introduction.

Screening tools with robust psychometric properties can help to reduce the inaccurate classification of people. Trevethan (2017) notes that tests with high sensitivity and specificity values can give some confidence when considering the results for an individual, but only when both are high. In the present study, both the CAIDS-Q and LDSQ had values that exceeded the recommended levels for developmental screening tests, and both had PPV and NPV of 75 % and above. Previous research has also shown that they perform at a similar level to short forms of intellectual assessments, but also have the benefit of being less time-consuming (McKenzie et al., 2014; Paxton et al., 2008).

This suggests that the properties of the measures themselves are robust and that they may be appropriate tools, at an individual level, for practitioners to use when screening for intellectual disability in people with ASD. While the LDSQ and CAIDS-Q are not replacements for full diagnostic assessment, they can help, and have helped, services to identify those who were not previously known

Table 2
The sensitivity, specificity, positive and negative predictive values, for the CAIDS-Q and LDSQ.

	CAIDS-Q Child subsample	LDSQ Adult subsample
Sensitivity	93.1	75
Specificity	88.5	95.6
Positive Predictive Value	90	75
Negative Predictive Value	92	95.6

to have an intellectual disability, prioritise assessments, and reduce waiting times for assessment (see McKenzie et al., 2021). The CAIDS-Q has also been highlighted as a helpful tool for professionals who are part of neurodevelopmental screening, assessment, and diagnosis pathways, such as teachers, nurses, and paediatricians (Rutherford et al., 2021). Similarly, staff working in a range of adult services may find the LDSQ useful as a way of facilitating the process of identification and differential diagnosis (McKenzie et al., 2021). As examples, the LDSQ has been highlighted for use as a screening tool in primary care by the Royal College of General Practitioners RCGP (2017) and for use by practitioners working in liaison and diversion services (NHS England and NHS Improvement (2019).

The screening tools also offer a way for those without the professional qualifications required to use particular standardised abbreviated intellectual assessments, such as parents, to have an evidence-based way to flag concern that a person is likely to meet the criteria for intellectual disability (see McKenzie et al., 2021).

6.1. Limitations and future research

The study does have limitations. The sample sizes were relatively small and the number of people with a diagnosis of intellectual disability, particularly within the adult sample, was smaller still. The performance of screening tools is influenced by prevalence rates of the target condition (Power et al., 2013). Further research with larger sample sizes and in other contexts can help determine the extent to which the results of the present study are able to be generalised more widely.

Basic demographic information, such as age and gender of participants was collected, but additional data, such as socioeconomic status and the relationship of the informant to the person may also be helpful to gather in future studies.

The CAIDS-Q is currently validated for children over 6 years old, meaning that its performance with children aged below 6 years is unknown. Early screening and diagnosis are desirable, and future research could explore the accuracy of the CAIDS-Q in children who are younger than 6 years old. While children with severe and profound intellectual disability can show early signs of developmental delays (American Psychiatric Association, 2021), the varied developmental trajectories of children can make accurate early diagnosis, particularly of mild intellectual disability, difficult. Such diagnoses may, therefore, be more likely to occur when children begin school and are faced with greater academic and social demands (Voigt & Accardo, 2016). Screening may be more reliable in school age children for the same reasons. In this context, the starting age of 6 years for use of the CAIDS-Q seems appropriate.

Previous research with the CAIDS-Q has found sensitivity to range between 82.2 % and 100 % and specificity to range between 82.8 % and 94.4 % for children aged 6 to under 8 years old, depending on the setting (McKenzie et al., 2019). The lower figures are above the recommended levels for developmental screening tools, but are lower than those for the older children (McKenzie et al., 2013). The higher figures were found in a recent study in paediatric settings and were equal to the sensitivity values and greater than the specificity figures values for the older children in the same settings (McKenzie et al., 2019).

The present study did not break the child sample down by age because there were only a small number of children in the younger age group. Further research, with a bigger sample size could compare sensitivity and specificity values of the CAIDS-Q in younger and older children.

The present study focused on screening for intellectual disability in autistic people because of the high co-occurrence between the two conditions. Future research could also explore the performance of the CAIDS-Q and LDSQ in those with other specific neurodevelopmental conditions, such as Attention Deficit Hyperactivity Disorder.

In conclusion, the results of the present study suggest that both the CAIDS-Q and LDSQ may be appropriate tools for screening for intellectual disability in autistic children and adults respectively, but further research with larger sample sizes is needed to confirm this.

Authors role

Karen McKenzie: Conceptualisation, Original data collection, Data analysis, Writing – original draft, **Dale Metcalfe:** Conceptualisation, Original data collection, review and editing the draft paper. **Aja L. Murray:** Conceptualisation, original data collection, data analysis, review and editing the draft paper.

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Data Availability

Data are available on reasonable request from the first author.

Declaration of interest

KM is a co-developer of the screening tools being evaluated in the study and receives a small income from their use. AM is the daughter of KM.

Data Availability

Data will be made available on request.

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