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The evaluation of a screening tool for children with an intellectual disability: The Child and Adolescent Intellectual Disability Screening Questionnaire

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Abstract

The study outlines the evaluation of an intellectual disability screening tool, the *Child and Adolescent Intellectual Disability Screening Questionnaire (CAIDS-Q)*, with two age groups. A number of aspects of the reliability and validity of the *CAIDS-Q* were assessed for these two groups, including inter-rater reliability, convergent and discriminative validity. For both age groups, a significant positive relationship was found between full scale IQ and *CAIDS-Q* score, indicating convergent validity. Significant differences were found in the *CAIDS-Q* scores between those with and without an intellectual disability, with the former group scoring significantly lower. The sensitivity and specificity of the *CAIDS-Q* were above 96.7% and 85.5% respectively for the younger group and 90.9% and 94.9% respectively for the older group. Limitations and implications of the study are discussed.

Keywords: Screening, intellectual disability; Child and Adolescent Intellectual Disability; Screening Questionnaire (*CAIDS-Q*)

1.Introduction

In order to be identified as having an intellectual disability an individual must meet three criteria. These are outlined in the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision and comprise of: significant impairments in general intellectual functioning (an IQ of less than 70); significant impairments in adaptive functioning, and onset before age 18 (American Psychiatric Association [APA], 2000).

By definition, children and adolescents with an intellectual disability will have some support needs that result from their impairments in cognitive and adaptive functioning. These needs will not be uniform and will be influenced by factors such as the child's individual cognitive profile, level of adaptive skills, and learning environment. Research does, however, suggest common difficulties that are shared by many people with an intellectual disability (Emerson, Hatton, Bromley, & Caine, 1998), including with working memory (Schuchardt, Gebhardt, & Mäehler, 2010) and understanding more abstract concepts such as time (Owen & Wilson, 2006). As a result, many children with an intellectual disability may require some additional support in relation to areas such as education (Simonoff et al., 2006), relationships (Heiman, 2000) and behaviour (Rzepecka, McKenzie, McClure, & Murphy, 2011). The family may also require support, as research suggests that having a child with an intellectual disability can impact on the family unit. This may be in positive ways (Blacher & Baker, 2007), however, for some families this may take a negative form, such as stress and poor psychological wellbeing (Gerstein, Crnic, Blacher, & Baker, 2009).

Early assessment and diagnosis is, therefore, important in order to appropriately meet and adapt to the changing needs of children with an intellectual disability (Herbert, 2006; McGinty & Fish, 1992), to identify and provide specific interventions to improve the skills and functioning of the child (Chadwick, Cuddy, Kusel, & Taylor, 2005), to help others

understand the child's needs (Goodman & Linn, 2003), and to provide support and information to family members (Hassall, Rose, & McDonald, 2005; Howie- Davis & McKenzie, 2007).

There can, however, be variability in the point at which children receive a diagnosis and delayed diagnosis can be associated with parental stress and dissatisfaction (see Watson, Hayes, & Radford-Paz, 2011 for an overview). It has been suggested that, where higher levels of satisfaction with the diagnostic process have been found in parents of older children, this may be due to relief at eventually receiving a diagnosis for their child (Hasnat & Graves, 2000).

A number of factors may influence the timing of the diagnosis, including: whether the diagnosis relates to a specific syndrome or is the less specific diagnosis of 'intellectual disability' (Quine & Rutter, 1994); whether relevant professionals such as education (Rae, McKenzie, & Murray, 2011) and primary care staff (McKenzie, Murray, Matheson, & McCaskie, 2000) have sufficient knowledge of what an intellectual disability is to recognise that a child may have one, and failure of legislation to specifically highlight the needs of this group of children (e.g. Maulik & Darmstadt, 2007; Scottish Government, 2004).

There may also be pragmatic reasons for delayed diagnosis. Accurate diagnosis of intellectual disability requires the individual assessment of adaptive skills, developmental history, and cognitive functioning (APA, 2000; British Psychological Society [BPS], 2001). The latter is commonly assessed using the Wechsler Scales of Intelligence (e.g. Wechsler, 2003), which can only be administered by a suitably trained and qualified professional (BPS, 2001). Both intellectual and adaptive behaviour assessments take some time to administer, score and interpret (Winters, Collett, & Myers, 2005). As a result, it is acknowledged that there is a need to find more efficient and effective ways to identify those who require support at an earlier stage (Evers & Hill, 1999). Screening tools, although not a replacement for a

comprehensive assessment, may facilitate the process whereby individuals who are suspected of having an intellectual disability are referred for a full diagnostic assessment or directed to an appropriate service to meet their needs. Some professional bodies, such as the BPS (2003), have recognised the pragmatic need to use screening tools, particularly in services where there are insufficient staff to meet high demands for diagnostic assessment in a timely way.

Recent reviews, both of screening tools which have been utilised to identify a range of disabilities, including intellectual disabilities in children (Maulik & Darmstadt, 2007), and which have looked specifically at screening for intellectual disabilities in children (McKenzie & Megson, 2011), concluded that, of those tools which were reviewed, there was no one screening tool that had sufficiently good psychometric properties for use with children with an intellectual disability.

There are, however, a number of challenges to developing a screening tool that has a universal application. Firstly, the purpose of the screening tool is likely to differ at the individual and service level. Screening may be used variously for epidemiological reasons, to determine the need for educational or clinical support, for research purposes or for identifying potentially vulnerable populations (see Maulik & Darmstadt, 2007 and McKenzie & Megson, 2011 for overviews). Similarly, the use of screening tools may differ from country to country. In countries where service provision is less well developed, for example, the priority may be to use screening tools to identify children with a range of disabilities, rather than having a specific focus on those with an intellectual disability (Chopra, Verma, & Seetharaman, 1999). Even if screening tools have the common purpose of identifying children with an intellectual disability, one single tool is unlikely to be suitable because cultural differences, e.g. in education and health provision, mean that items that are highly discriminative in one country may not be so in another. Maulik and Darmstadt (2007), speaking in general of screening

tools for disability in children, note that the translation of standardised assessments for use in other countries may obscure cultural differences in the language used to describe symptoms. Such differences may impact on the psychometric properties of the translated assessment.

These difficulties make it unlikely that a single screening tool with universal application will be developed, however the reviews by Maulik & Darmstadt (2007) and McKenzie & Megson (2011) suggest that the need for a valid and reliable screening tool for use with children with an intellectual disability remains. In this context, the present study aims to evaluate some of the psychometric properties of a screening tool, the *Child and Adolescent Intellectual Disability Screening Questionnaire (CAIDS-Q)* with children of two age groups from a Western developed, English-speaking culture.

2. Method

2.1 Ethical Approval

As the data were being collected from pre-existing assessment and diagnostic information from clinical case-notes in Scotland, and the study did not involve direct patient contact, approval for the study was obtained from the Caldicott Guardians and appropriate clinicians in the participating health boards.

2.2 Developing the screening tool

The development of the screening tool was guided by the principles that underpin the development of all good psychometric tools (e.g. Terwee et al., 2007): it should be valid, reliable and standardised with a group of people whose characteristics are representative of the population with whom it is intended to be used. Many aspects of validity and reliability can be measured. The present study reports on face, content, criterion (convergent and discriminative) and construct validity, internal consistency and inter-rater reliability of the *CAIDS-Q*. The particular desired characteristics of screening tools were also taken into

account. These include good sensitivity and specificity i.e. the ability to correctly identify true positives (in this case those with an intellectual disability) and true negatives (those who don't have an intellectual disability) respectively (Glascoe, 2005; Sonnander, 2000). In general, sensitivity values should exceed 70% and specificity values should exceed 80% in order to be considered satisfactory (American Academy of Pediatrics, 2001; Glascoe, 2005), although the exact balance may depend on the purpose of the screening tool and whether it is more important to accurately identify those who fall within or out with a particular category (Charman et al., 2007). In the present study, it was considered that it was more important that the screening tool had better sensitivity relative to specificity in order to increase the probability of correctly identifying children and adolescents who have an intellectual disability.

The screening tool was also developed to be used by a range of professional and non-professional staff, without requiring extensive training or particular qualifications.

Evaluations of the adult version of the screening tool, the *Learning Disability Screening Questionnaire (LDSQ)*: McKenzie & Paxton, 2006) indicated that it was possible to develop a screening tool with these characteristics (Jackson, 2011).

2.3 Item selection

Items for inclusion in the *CAIDS-Q* were selected based on the following criteria: items which had been identified in previous research as being possible indicators of intellectual disability, for example ability to tell the time (Sharp, Murray, McKenzie, Quigley, & Patrick, 2001); items which were likely to be indicative of intellectual disability in childhood, such as educational support (Burton, 1997); items which had been found to have good sensitivity and specificity in the adult version of the screening tool (*LDSQ*: McKenzie & Paxton, 2006) and which appeared to be equally applicable for children e.g.

literacy skills; items which were reflected in validated measures of adaptive functioning (e.g. Harrison & Oakland, 2000) which were thought likely to discriminate between children with and without an intellectual disability, and items that would be relatively quick and easy to measure.

In order to examine face validity, the initial items which were chosen for inclusion were then discussed and evaluated by a small group of professionals with expertise and experience in working with children with an intellectual disability and typically developing children. This group included three clinical psychologists and a mental health worker. Following these discussions, 11 items were chosen for inclusion.

The initial assessment (which was named the *Child Learning Disability Screening Questionnaire: CLDSQ*) was then piloted with a sample of 33 children with and without an intellectual disability (McKenzie, Megson, & Paxton, 2008). This pilot showed that the *CLDSQ* scores increased with the child's age, indicating that the initial screening tool items may not be discriminating across the age ranges. On the basis of the results of the pilot study, and following further input from the professional group, four items were excluded from the screening questionnaire, leaving seven items which covered educational support, literacy skills, social relationships, previous contact with services and self-care. The final 7 item screening tool was renamed the *Child and Adolescent Intellectual Disability Screening Questionnaire (CAIDS-Q)* to differentiate it from the earlier 11 item pilot version. All subsequent analyses outlined below relate to the *CAIDS-Q*.

2.3.1 Item scoring

All 7 items were scored as 'yes' or 'no' based on whether it applied to the individual or not, e.g. whether the child had had previous contact with intellectual disability services. One point was given for each 'yes' response with the exception of two items which were reverse scored. The total number of points were added and converted to a percentage score to

allow for any items where information was missing. The minimum score was zero and the maximum 100. The higher the score, the less likely the individual was to have an intellectual disability.

2.4 Validation of the CAIDS-Q

2.4.1 Procedure

In order to assess some aspects of the validity of the *CAIDS-Q*, data were collected from four Scottish National Health Service (NHS) community child and adolescent/intellectual disability services. Information was gathered using routinely collected assessment and diagnostic data from case-notes for all children and adolescents who had been referred to the services and had undertaken an assessment to determine whether they had an intellectual disability or not. The information collected included scores on *CAIDS-Q* items, gender, age and full scale IQ. These data were recorded anonymously. Determination of whether the participant had an intellectual disability or not was based on the clinical diagnosis in the case notes, as assessed by the independent clinician in the NHS service. In general the majority of clinicians had assessed intellectual functioning using either the *Wechsler Intelligence Scales for Children – fourth edition (WISC IV: Wechsler, 2003)* or the *Wechsler Adult Intelligence Scales- third edition (WAIS III: Wechsler, 1997)* depending on the age of the child. Adaptive functioning had been predominantly measured by either the *Vineland Adaptive Behaviour Scales – Second Edition (Vineland II: Sparrow, Balla, & Chicchetti, 2005)* or the *Adaptive Behaviour Assessment System - Second Edition (ABAS-II: Harrison & Oakland, 2003)*; both of which are standardised assessments of adaptive functioning. Data were excluded if there was insufficient information to score the *CAIDS-Q*, if there was insufficient information to determine if the individual concerned had an intellectual disability or not, or if the assessment for children 16 and under had been carried out using an assessment of intellectual functioning that pre-dated the introduction of the *WISC IV* (Wechsler, 2003).

2.5 Participants

Participants' data were grouped according to two age categories, in order to allow separate analyses. This followed results from the initial pilot study (McKenzie et al., 2008), which found a significant positive correlation between the screening assessment score and age, indicating that the pilot screening tool items were not sensitive to age. The younger age group included 130 children aged 8 years to 11 years and 11 months and the older age group included 156 children aged 12 years to 18 years. The cut-off age of 12 years was chosen because, in many areas in the UK, children make the transition from primary to secondary education at around this age. It was, therefore, thought likely that any developmental difficulties may be highlighted at around age 12 when the child enters a new environment and has to cope with new educational and social demands.

2.5.1 Younger sample

In the younger age group, 61 individuals had an intellectual disability and 69 did not. Of those with an intellectual disability, 35 were male and 24 were female. Full Scale IQ ranged from 39-68, with a mean score of 53.58 (SD = 8.01). Ages ranged from 96 to 143 months (mean = 120, SD = 12.74). Of those without an intellectual disability, 46 were male and 23 were female. Full scale IQ ranged from 70 to 138, with a mean score of 93.38 (SD = 18.99). Ages ranged from 96 to 143 months (mean = 116.72, SD = 13.76). No significant differences were found between those with and without an intellectual disability in relation to gender ($\chi^2 = .74$, $df = 1$, $p = .39$) or age ($t(128) = 1.41$, $p = .16$)

2.5.2 Older sample

In the older age group, 77 individuals had an intellectual disability and 79 did not. Of those with an intellectual disability, 44 were male and 33 were female. Full Scale IQ ranged from 30-69, with a mean score of 53.71 (SD = 10.39). Ages ranged from 144 to 205 months

(mean = 172.61, SD = 15.95). Of those without an intellectual disability, 53 were male and 24 were female. Full scale IQ ranged from 62 to 125, with a mean score of 83.84 (SD = 12.93). The individual with an IQ of 62 did not meet the criterion for intellectual disability of a significant impairment in adaptive functioning. Ages ranged from 144 to 216 months (mean = 170.08, SD = 16.19). No significant differences were found between those with and without an intellectual disability in relation to gender ($\chi^2 = 2.26$, $df = 1$, $p = .13$) or age ($t(154) = .98$, $p = .33$).

2.6 Inter-rater reliability

Two raters independently scored 28 sets of data on the same day to determine the inter-rater reliability of the *CAIDS-Q*. The first rater was the first author and the second was a research volunteer who was attached to an NHS psychology department and who was completely independent of the study. The data were then analysed using Kappa. Following Cramer (1998) and Clark-Carter (1997) a Kappa value of between 0.4 and 0.7 was considered to indicate fair to good levels of agreement; 0.7 acceptable agreement and above and 0.75 excellent agreement.

2.7 Construct validity

2.7.1 Dimensionality

The uni-dimensionality of the scale was assessed using a single group (those with intellectual disability and those without combined) confirmatory factor analysis. A one factor model was estimated in Mplus 6.0 using weighted least squares (WLS) estimation. For the purposes of scaling/identification, the loading of 'time' on the common factor was fixed to 1.0. Model fit was evaluated using comparative fit indices (CFI) and Tucker Lewis Index (TLI) as incremental fit indices, and Weighted Root Mean Square Residual (WRMSR) and Root Mean Square Error of Approximation (RMSEA) as baseline fit. Good fit is indicated by

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CFI and TLI > 0.95 (Hu & Bentler, 1999), WRMSR values of <0.90 (Yu, 2002) and RMSEA <0.08 (Schermelel-Engel et al., 2003).

2.7.2 Internal consistency

Internal consistency is defined as the extent to which the individual items on a scale or subscale intercorrelate and can, therefore be considered to be measuring the same construct (Terwee et al., 2007). The internal consistency of the *CAIDS-Q* was assessed using Cronbach's alpha. Following Terwee et al. (2007) a value exceeding .70 was considered to be acceptable.

2.8 Criterion validity

This is the extent to which scores on a given measure are consistent with those of a gold standard measure (Terwee et al., 2007). In the present study, this was measured by the convergent and discriminative validity of the *CAIDS-Q*.

2.8.1 Convergent validity

Convergent validity was assessed by examining the extent to which the scores on the *CAIDS-Q* were correlated with full scale IQ as measured by either the *WISC IV* (Wechsler, 2003) or the *WAIS III* (Wechsler, 1997) depending on the age of the child.

2.8.2 Discriminative validity

2.8.2.1 Determining sensitivity and specificity of the CAIDS-Q

A receiver operating characteristic (ROC) curve analysis (Schoonjans, 1998) was used to determine the sensitivity and specificity of the *CAIDS-Q*. Participants were categorised as having an intellectual disability or not according to the procedure outlined in section 2.4.1. The choice of cut-off score was determined by prioritizing the correct identification of those who are likely to have an intellectual disability over those who are not i.e. sensitivity relative to specificity.

2.8.2.2 Comparison of CAIDS-Q scores by diagnosis

An independent t-test was used to determine if there was a significant difference in *CAIDS-Q* scores between those who had a diagnosis of intellectual disability and those who did not.

2.9 Item discrimination across the age ranges

The relationship between *CAIDS-Q* score and age was examined for the younger and older groups separately and for the total sample, to determine whether there was a relationship between *CAIDS-Q* and age.

3. Results

3.1 Inter-rater reliability

Kappa values for inter-rater agreement ranged from 0.92 to 1.00, indicating excellent inter-rater reliability for all of the *CAIDS-Q* items.

3.2 Construct validity

3.2.1 Dimensionality

Based on an RMSEA value of .10, a weighted root mean square residual value of 1.13, a Tucker-Lewis index of .98 and a Comparative fit index of .99, the fit of a one factor model to the data was reasonable to good. This supported the uni-dimensionality of the scale.

3.2.2 Internal consistency

High internal consistency of the scale was indicated by a Cronbach's alpha of .88.

3.3 Criterion validity

3.3.1 Convergent validity

Convergent validity was indicated by a significant Pearson's correlation between *CAIDS-Q* scores and full scale IQ in both the younger group ($r(126) = 0.783, p < 0.001$) and the older group ($r(152) = 0.788, p < 0.001$). Both results indicate a large effect size (Cohen, 1992).

3.3.2 Discriminative validity

3.3.2.1 Determining sensitivity and specificity of the *CAIDS-Q*

. For the younger children the area under the curve was found to be .95, indicating a significant ability ($p < 0.001$) to discriminate between those with and without an intellectual disability. A cut-off score of 62 was chosen that gave sensitivity of 96.7% and specificity of 85.5%. For the older group the area under the curve was .97, again indicating a significant ability ($p < 0.001$) to discriminate between those with and without an intellectual disability. A cut-off score of 64 was chosen that gave sensitivity of 96.1% and specificity of 84.8%.

3.3.2.2 Comparison of *CAIDS-Q* scores by diagnosis

An independent t-test illustrated, for the younger group, that the *CAIDS-Q* scores of those who had an intellectual disability (mean = 15.97, SD = 20.64), were significantly lower ($t(128) = -16.364, p < 0.001; d = 2.89$, large effect size) than those who did not (mean = 79.97, SD = 23.58). Similarly for the older group, the *CAIDS-Q* scores of those who had an intellectual disability (mean = 20, SD = 20.90), were significantly lower ($t(154) = -19.339, p < 0.001; d = 3.09$, large effect size) than those who did not (mean = 81.54, SD = 18.82).

3.4 Item discrimination across the age ranges

Pearson's correlations illustrated that no significant correlations existed between age and *CAIDS-Q* scores for either group 1 ($r(130) = -.078, p = .377$) group 2 ($r(156) = -.077$

$p=.336$) or the whole sample ($r(286) = -.024, p=.692$), indicating that the *CAIDS-Q* items were applicable across the age ranges tested.

4. Discussion

The present study aimed to examine some aspects of the validity and reliability of the *CAIDS-Q* as a screening tool in two age groups of children, those aged between 8 and 11 years 11 months and those aged 12-18 years.

A number of approaches to ensuring the face validity of the *CAIDS-Q* were adopted, including basing the item selection on existing research, obtaining feedback from experienced professionals working within child and child intellectual disability services, and undertaking a pilot project. The final 7 item structure of the *CAIDS-Q* was supported in two ways: a confirmatory factor analysis supported the uni-dimensionality of the screening tool and good internal consistency was indicated by a high Cronbach's alpha score. This supports the construct validity of the *CAIDS-Q*.

The inter-rater reliability of the screening tool was indicated by the fact that all of the items obtained significant Kappa scores at values which equated to 'excellent' levels of agreement (Clark-Carter, 1997). As the *CAIDS-Q* was designed to be used by a range of people, both professional and non-professional, with minimal training, it is important that it demonstrates good inter-rater reliability, suggesting that it can be used reliably by different people.

The criterion validity of the *CAIDS-Q* was also examined. The convergent validity of the *CAIDS-Q* was supported for both age groups, with significant positive relationships being found between full scale IQ and *CAIDS-Q* scores. Thus, the higher the child's IQ, the higher their *CAIDS-Q* score will be.

The discriminative validity of the screening tool was also supported for both age groups, as indicated by the finding that those children with a diagnosis of intellectual disability had significantly lower *CAIDS-Q* scores than those who did not have this diagnosis. Two ROC analyses were conducted separately for each age group and in both cases, the *CAIDS-Q* was found to significantly discriminate between those with and without an intellectual disability. In addition, sensitivity and specificity values of the screening tool were very similar in both age groups and exceeded the 80% range which is commonly taken to indicate an acceptable level of discrimination by a screening tool (AAP, 2001; Glascoe 2005).

Importantly, the *CAIDS-Q* also appeared to show sensitivity to age, with no significant relationship being found between age and *CAIDS-Q* score in either of the age groups or in the overall sample. This suggests that the items are sufficiently robust to continue to discriminate between children with and without an intellectual disability over time and despite the developmental changes that occur with age. It can be challenging to develop a screening tool that has developmental sensitivity, given that children acquire different skills at different ages and that this acquisition can also be influenced by external factors (AAP, 2001; Glascoe, 2005). Indeed the initial pilot study of the *CLDSQ* failed to achieve this, as was indicated by a significant positive correlation between the screening tool score and age.

The present study indicates that the face, construct, convergent and discriminative validity, and inter-rater reliability of the *CAIDS-Q* are supported and that the items are applicable across the included age groups. It may, therefore, offer a useful means of identifying children who are likely to have an intellectual disability in order to facilitate intervention at an earlier stage (Guralnick, 2005), provide targeted educational support (Sonnander, 2000), help ensure referrals to specialist services are more appropriate (BPS,

2003) or in order to identify particular groups of children for research purposes (Charman et al., 2007).

The study does, however, have some limitations. Only some aspects of the validity and reliability of the *CAIDS-Q* were examined and other important aspects such as test-retest reliability were not measured. In addition, the study only focused on children aged 8 or older. While some individuals may not receive a diagnosis of intellectual disability until they are teenagers (Simonoff et al., 2006) or even adults (Hamilton, 2006), earlier identification of those children who are likely to have an intellectual disability would be preferable. Research does, however, indicate that accurate screening of young children is difficult to achieve (Bornholt, Spencer, Ouviaer, & Fisher, 2004; Sonnander, 2000). A useful area of future research would be to examine the extent to which the *CAIDS-Q* demonstrates validity and reliability with children under 8 years old.

A second limitation is that the *CAIDS-Q* was standardised with a sample of children that had been referred to NHS child/intellectual disability services in the UK, a developed, English speaking country, and it can not be assumed that its psychometric properties will be the same when used with children from different settings or countries. For example, there has been an increasing interest in identifying children and adolescents who come in contact with forensic services (Ford, Andrews, Booth, Dibdin, Hardingham, & Kelly, 2008). Recent research with the adult version of the intellectual screening tool (McKenzie, Michie, Murray & Hales, 2012), from which the *CAIDS-Q* was partly developed, demonstrated both convergent and discriminative validity of the *LDSQ* in forensic settings, but suggested that a higher cut-off score may increase the sensitivity of the tool when used in such services. Future research with the *CAIDS-Q* is required to establish the extent to which its psychometric properties are consistent across settings and countries.

.Finally, it should be emphasised that the *CAIDS-Q*, as with any screening tool, only represents the first step in the process towards accurate diagnosis and identifying the support needs of a child with an intellectual disability, and it should not be viewed as a substitute for a full diagnostic assessment. It may, however, offer a means of facilitating the identification of children who seem likely to have an intellectual disability and, as a result, expedite the process of referral to specialist services for diagnosis.

5. Conclusion

In conclusion, the present study provides evidence that the *CAIDS-Q* has demonstrated a number of different forms of validity and reliability, when used with two age groups of children who were referred to child/intellectual disability health services. This suggests that it may represent a useful screening tool to identify those children aged 8 and over who are likely to have an intellectual disability. Further research is required to evaluate the *CAIDS-Q* with a younger age group, across a wider range of settings and in countries other than the UK.

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