Identifying children with an intellectual disability: Evaluating the Child and Adolescent Intellectual Disability Screening Questionnaire in Paediatric Neurodevelopmental clinics

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Abstract

Aim: To evaluate the psychometric properties of the Child and Adolescent Intellectual Disability Screening Questionnaire (CAIDS-Q) in paediatric neurodevelopment clinics in Scotland.

Methods: Participants were 181 children (aged 6-18 years) attending paediatric services in Scotland, divided into three age groups according to previous CAIDS-Q standardisation cut-off scores. Fifty four (mean age = 117 months, SD = 29.9, male = 37) met the criteria for intellectual disability (ID) and 127 did not (mean age = 120.1 months, SD= 32.7, male =88). A number of psychometric properties of the CAIDS-Q were evaluated, including test-retest and inter-rater reliability, convergent validity, sensitivity, specificity, and positive and negative predictive value based on existing cut-off scores.

Results: Significant positive relationships were found for all three age groups between CAIDS-Q scores and measures of intellectual and adaptive functioning. Test-retest reliability ranged from 'moderate' to 'almost perfect', while inter-rater reliability ranged from 'fair' to 'almost perfect'. Sensitivity and positive predictive value were 100% for all groups and specificity was between 83% and 94% depending on age. Negative predictive values ranged from 75-91%.

Interpretation: The CAIDS-Q would appear to show psychometric properties that would support its use as a screen for ID in paediatric neurodevelopmental settings.

What this paper adds

- The Child and Adolescent Intellectual Disability Screening Questionnaire (CAIDS-Q) showed good psychometric properties
- It identified all participating children who met the criteria for intellectual disability (ID)
- Between 83 and 94% of children without ID were also correctly identified
- The results suggest the CAIDS-Q could help paediatricians identify children with ID

Short title: Evaluating the CAIDS-Q

It is challenging to determine an accurate prevalence rate for children with ID because studies can differ markedly in respect of the participants, methodology, assessments, and criteria used to determine ID. Recent studies suggest that prevalence ranges from approximately 1.2-2% for all categories of ID for children aged up to 17 years.[1,2]

By definition, those children meeting the diagnostic criteria for ID have significant difficulties with their intellectual and adaptive functioning.[3] The early identification of children with ID is, therefore, important in order to inform options for support and intervention, as well as heightening awareness of common comorbid conditions and associated issues,[4] such as an increased risk of health problems and behaviours that challenge.[5] Early identification can also facilitate access to services and other resources, prompt regular monitoring for associated developmental, emotional and behavioural difficulties[6] and, if the ID was caused by a genetic condition, provide important information about prognosis and risk of recurrence.[4]

The identification of ID, particularly in those with mild neurodevelopmental difficulties, is challenging and may not happen until late childhood, adulthood or, in some cases, never. [5,7] The diagnosis of ID can also be complex, demanding for the child and family, resource and time intensive,[8] and reliant on assessment by an appropriately qualified psychologist.[9] All of these factors can lead to delays in diagnosis. Paediatricians play a key role in the identification of developmental disabilities in children[10] but while they may identify a child as having global developmental delay (GDD), this is not synonymous with ID. Research[11] with 140 children with a diagnosis of GDD found the majority had an IQ above the intellectual disability range and 20% had an IQ in the average range.

Screening questionnaires offer one means of helping to identify children who should be prioritised for full diagnostic assessment. Paediatric neurodevelopment services offer an obvious setting where screening for ID could take place, as they are often the first point of

contact for children with neurodevelopmental difficulties and many paediatric services liaise closely with colleagues in psychiatry and clinical psychology.[12] There is, however, a dearth of measures that are specifically designed to identify children with ID, which have strong psychometric properties, and which have been standardised for use with a paediatric neurodevelopmental population.[13] The Child and Adolescent Intellectual Disability Screening Questionnaire (CAIDS-Q) has been found to have good psychometric properties in other clinical settings, including child and adolescent mental health[14, 15] and forensic services[16] but has not been validated for use in paediatric neurodevelopmental settings.

It is important that any measure is evaluated with a representative group of children from a setting in which it is intended to be used, as the performance, as well as the feasibility of a measure can vary depending on the characteristics of population and situation in which it is used.[17] For example, the number of false positives will be greater in contexts in which the base rate of ID is low. The present study, therefore, aims to evaluate a number of the psychometric properties of the CAIDS-Q when used in paediatric neurodevelopmental services.

Method

Procedure

Ethical approval for the study was obtained from the National Health Service Integrated Research Approval System and from the local authorities within which the study took place. Parents of children who were attending neurodevelopmental paediatric clinics in the south-east of Scotland were provided with information about the study by their paediatrician and with contact details of the research team should they have any questions. Those who wished to participate signed and returned a consent form. They were then contacted by a member of

the research team to arrange a suitable time to complete assessments. Parents could complete the parental assessments independently or with support from a researcher if they preferred.

Children were assessed at home, at school, or at central neurodevelopmental paediatric service premises depending on the preference of the parent. These assessments were conducted by chartered clinical psychologists and/or supervised clinical psychology assistants. In addition, demographic information including age and gender was gathered and, where parents gave consent, information was obtained from the child's clinical case notes in relation to reason for referral and any existing conditions or diagnosis.

The conditions used to establish whether the child currently met the diagnostic criteria for ID or not, for the purposes of the project, were based on those used in clinical practice of significant impairment in intellectual and adaptive functioning and childhood onset.[3,9] These were operationalised as: an IQ of less than 70 as measured by the Wechsler Intelligence Scales for Children – Fourth Edition (WISC IV[18]) and significant impairment in adaptive functioning, based on assessment by the Adaptive Behaviour Assessment System (ABAS II/III[19,20]). As all of the participants were children, the childhood onset criterion was already met for all participants. Children were considered to currently meet or not meet the criteria for ID based on their functioning at that time.

Participants

Participants were children and young people aged between 6 and 18 who were attending one of the paediatric clinics in the study location. All but one individual was introduced to the project via a neurodevelopmental paediatric service. The paediatric neurodevelopmental clinics were second and third tier. All took place in the context of multidisciplinary support for the child or young person. Their parents/guardians completed the ABAS II/III and CAIDS-Q. Children were excluded if English was not their first language as the WISC IV was standardised

on an English-speaking British population. A total of 226 children and their parents/guardians participated, of whom 181 completed all the assessments required for the analysis. As recruitment was via paediatricians, the number and characteristics of those who were invited to participate, but chose not to, is unknown. Children were grouped into three age categories based on previous determinations of cut-off scores:[14, 15] ages 6 to 7 years, 11 months, and 30 days (Group 1); ages 8 to 11 years, 11 months, and 30 days (Group 2); and ages 12 to 18 (Group 3). Table I provides information about the age and gender of the children in each group and for the total sample.

INSERT TABLE I

The most common reasons for referral to the neurodevelopmental paediatric clinics were concerns about speech and language, behaviour, and social/emotional development, with the majority of children having been referred for two or more reasons.

Measures

Child and Adolescent Intellectual Disability Screening Questionnaire [14, 21](CAIDS-Q). This is a short, seven item screening tool that is scored by giving Yes/No answers to items relating to literacy, current and previous support from clinical and educational services, friendships, and basic functional skills. Responses are converted to a percentage score, with a lower score indicating an increased likelihood of having ID. The total percentage score is compared against a cut-off score for the age group of the child to identify whether he/she is likely to have ID. The CAIDS-Q has been found to have good psychometric properties in a range of settings.[14, 15, 16] It takes approximately 5 minutes to complete and can be completed by someone who knows the child well and/or directly with the child, depending on their level of ability.

Wechsler Intelligence Scales for Children – Fourth Edition (WISC IV[18]). The WISC IV is a commonly used assessment of intellectual functioning with good psychometric

properties[22] which has been standardised for use in the United Kingdom (UK). It provides four composite scale index scores: Verbal Comprehension, Perceptual Reasoning, Working Memory and Processing Speed, and a Full Scale IQ.

Adaptive Behaviour Assessment System – Second/Third Edition (ABAS-II/ABAS III[19,20]). This standardised assessment of adaptive functioning provides scores in the domains of: Conceptual, Practical, and Social; and an overall indicator of adaptive functioning: General Adaptive Composite (GAC). The ABAS has been found to have good psychometric properties[23] although was standardised with a United States sample, rather than a UK sample. The assessment was updated during the course of the project and the latest version was used once it became available.

Evaluation criteria

A number of important criteria have been identified against which assessments more generally, and screening tools in particular, can be evaluated.[10, 17, 24] The present evaluation reports on a number of these (required sample size was based on effect size estimates from previous studies evaluating the CAIDS-Q[14,16]) and utilised a range of descriptive and inferential statistics:

- Inter-rater reliability was assessed by comparing the CAIDS-Q ratings by the parent/guardian with the performance of the child on the same items, where direct assessment was possible. The data were then analysed using Kappa to give a measure of agreement for individual items.
- Test-retest reliability was assessed by asking parents to complete the CAIDS-Q on two separate occasions approximately two weeks apart. Kappa was used as an estimate of test-retest reliability for individual items. A Pearson's correlation was also used to assess agreement on overall CAIDS-Q percentage score.

- Convergent validity was evaluated by correlating CAIDS-Q scores with WISC IV Full Scale IQ (FSIQ) scores and ABAS GAC scores. These latter measures represent gold standard ways of assessing the criteria for ID of significant impairment in intellectual and adaptive functioning respectively. Support for convergent validity of the CAIDS-Q would be represented by a significant, positive correlation with these measures.
- Sensitivity and specificity of the CAIDS-Q was based on existing cut-off scores for the three different age groups. The acceptability of these values was based on the guidance that sensitivity values should usually exceed 70% and specificity values should exceed 80%. [10, 24]
- The positive predictive power – i.e. the ratio of those correctly identified as having ID to all those identified as having ID by the CAIDS-Q – and the negative predictive power – i.e. the ratio of those correctly identified as not having ID to all those identified as not having ID by the CAIDS-Q – were also calculated based on existing CAIDS-Q cut-off scores for the three different age groups and compared against diagnostic status in relation to ID. As Glascoe[24] notes, there is no consensus as to what constitutes an acceptable value for positive and negative predictive power.

Results

Of the 181 participants, 54 (30%) were found to currently meet the criteria for ID. No significant relationship was found between age group and the proportion of children/young people diagnosed as having ID or not ($\chi 2 = 2.184$, df = 2, p = .336). More boys than girls participated in the study overall and were represented in those with and without ID, however

there was no significant relationship between gender and whether the person had ID or not ($\chi 2$ =.011, df = 1, p = .918).

Inter-rater reliability and test–retest reliability

Table II provides the Kappa values for inter-rater agreement for the four items where direct assessment of the child was carried out and test-retest values for all CAIDS-Q items. Sample size numbers varied slightly for some items, for example if a parent responded 'don't know' or omitted an item on the CAIDS-Q at either time point this was excluded from the reliability analyses. A significant positive correlation was found between CAIDS-Q total percentage scores across the two week time period (r (32) = 0.896, p<0.001).

INSERT TABLE II

Convergent validity

Table III provides information about the CAIDS-Q, FSIQ, and ABAS GAC scores for each age group and the total sample.

INSERT TABLE III

Table IV provides the correlations between the total CAIDS-Q percentage score, FSIQ, and ABAS GAC for the three age groups and the total sample. Correlations between FSIQ and ABAS GAC are given for comparative purposes.

INSERT TABLE IV

All correlations were significant at p<0.05 or less. Correlations between CAIDS-Q and FSIQ/ABAS GAC were greater than those between FSIQ and ABAS GAC for all age groups and the total sample.

Sensitivity, specificity, and positive and negative predictive power

The sensitivity and positive predictive value was 100% for all age groups and the total sample. Specificity and negative predictive values were 94.4 and 88.2% respectively for group 1, 82.8 and 75% respectively for group 2, 90.9% for both values for group 3 and 88.2 and 78.3% respectively for the total sample. Of the 15 children who were incorrectly identified by the CAIDS-Q as having ID, nine had an ABAS GAC score in the 'extremely low' range and a further two had a FSIQ in the 'extremely low' range (i.e. a score falling under two standard deviations below the mean; percentile ≤ 2.2). The remaining four children were performing in the 'low average' or below range in terms of intellectual and/or adaptive functioning. None of the 15 had both their ABAS GAC and FSIQ in the average range or above.

Discussion

It is recognised that screening can help facilitate earlier identification of ID; however, while a number of measures are available that can help identify developmental difficulties in a range of different domains,[24] few exist that are specific to ID and are validated for use in neurodevelopmental paediatric clinics. This study aimed to evaluate a number of the psychometric properties of the CAIDS-Q when used in such settings.

The study found that, of the 181 children who participated, 54 (30%) currently met the criteria for ID. This is considerably higher than estimated population prevalence rates based on recent studies of approximately 2%.[1,2] This confirms expectations that a greater number of children with ID would be found in neurodevelopmental paediatric services than are in the population as a whole. Our study is – to the best of our knowledge – the first to attempt to provide relevant prevalence data for this setting.

The inter-rater reliability of the CAIDS-Q items was good, with the exception of the item relating to writing which was 'fair.' This lower reliability may be because, when tested

directly, the children were asked to write a set piece of text, whereas it is likely that parents were basing their judgment on experience of their child's writing ability across a range of different texts. The test-retest reliability of the CAIDS-Q was good, both across all individual items and for total percentage score, indicating that parental ratings of items on the CAIDS-Q are likely to be consistent over a short time period.

In terms of convergent validity, CAIDS-Q scores were found to correlate both positively and significantly with FSIQ (range .62-.79) and ABAS GAC (range .48-.60) scores. This is consistent with previous research which has also found the CAIDS-Q to have good convergent validity with measures of adaptive and intellectual functioning when used in other settings [14, 15, 16, 26] and that CAIDS-Q scores can be used, with caution, to give an approximation of IQ when other information about intellectual functioning is not available.[27] The correlations found with the CAIDS-Q in the current study were all stronger than between FSIQ and ABAS GAC (range .47-.49), i.e. the CAIDS-Q was found to be more strongly related to these measures of intellectual and adaptive functioning than FSIQ and ABAS GAC scores were to each other. Intellectual and adaptive functioning are considered to be related but separate concepts, and previous research has found that the three main aspects of adaptive functioning – social, conceptual, and practical – have a differential relationship with general intelligence, particularly in individuals with a lower IQ.[28] However, the CAIDS-Q was specifically designed to measure intellectual disability and was thus designed to correlate with both IQ and adaptive functioning. .

The CAIDS-Q was also found to accurately identify children with and without ID, correctly identifying all children with ID in the three age groups and between 83% and 94% of children who did not have ID in the three age groups and overall. These values are consistent with those found when using the CAIDS-Q with other groups of clinically referred children.[14, 16] All values were above the levels identified as acceptable for a screening tool.[10,

[24] The positive predictive value of the CAIDS-Q was 100 for all groups, meaning that all those children who were correctly identified as having ID on the measure, represented all of those who had ID based on diagnostic assessment. The negative predictive values ranged between 75% and 91% depending on the age group. There is no general agreement as to what is acceptable in terms of positive and negative predictive values, but Glascoe[24] notes that values of 30%–50% are not unusual in practice.

The balance between sensitivity and specificity of any screening tool is determined by a number of factors, not least whether it is more important to identify those with or without a particular condition. While the general prevalence rate of ID in paediatric services is unknown, it is likely to be higher than that found in general population studies because of the nature of the service. What these results for the CAIDS-Q mean in practice can be seen if we use an estimated prevalence rate of ID for neurodevelopmental paediatric settings that is at least equivalent to that found in recent studies of approximately 2%. For the overall sample, for every 100 children screened with the CAIDS-Q, two will have ID and will be correctly identified as such, given the 100% sensitivity of the tool. For the 98 children who do not have ID, 86 will be correctly identified as such, based on the 88.2% specificity of the CAIDS-Q. This leaves 12 children who will be incorrectly identified as having ID when they do not and who will have undergone further assessment.

In the present study, 15 children were incorrectly identified as having ID based on their scores on the CAIDS-Q. Eleven of these children had significant difficulties with their adaptive or intellectual functioning, based on their ABAS GAC and FSIQ scores respectively, and none of the 15 performed in the average range or above on both of these areas. This suggests that the CAIDS-Q may be useful for identifying children who have significant difficulties in adaptive or intellectual functioning even if the child does not meet the criteria

for ID at that point. Such children could then be followed up for further screening or assessment at a future point.

Research suggests that, based on financial considerations alone, the costs associated with over-identification of children with a disability are much less than the lifetime cost of under-identification and the subsequent impact of this.[29] The cut-off scores for the CAIDS-Q were developed with this consideration in mind.

Overall, the results suggest that the CAIDS-Q has robust psychometric properties, for those areas which were assessed, when used in paediatric settings. The study did, however, have some limitations. The response rate to the study was unknown, as recruitment was via paediatricians, rather than conducted directly by the researchers. Some of the analyses, such as test-retest reliability, were based on relatively small sample sizes because the parents did not always remember or have the time to complete the CAIDS-Q on a second occasion. In addition, the sample included very few children who had a more severe level of ID. This may be because their diagnosis of ID was already known and so parents were less motivated to participate in the study. While this may have resulted in a somewhat biased sample of children who were not necessarily representative of all children with ID who accessed neurodevelopmental paediatric services, children with a mild ID are more likely to have their ID overlooked[30] and it is this group of children that the CAIDS-Q was primarily designed to help identify.

In conclusion, the CAIDS-Q was found, overall, to have acceptable levels of test-retest and inter-rater reliability, strong convergent validity when correlated with measures of cognitive and adaptive functioning, and good ability to discriminate accurately between children with and without ID. This indicates that it would be an appropriate screening measure to identify children in neurodevelopmental paediatric clinics who are likely to have ID and who should be prioritised for further diagnostic assessment.

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Table I: Age and gender of each group and the total sample

	ID[a]				Not ID			
	Age (months)		**Gender**		**Age (months)**		**Gender**	
	Range	**Mean (SD)**	**Male *N* (%)**	**Female *N* (%)**	**Range**	**Mean (SD)**	**Male *N* (%)**	**Female *N* (%)**
Group 1	72–95	81.3 (7.0)	9 (60)	6 (40)	72–95	83.5 (8.2)	26 (72)	10 (28)
Group 2	96–142	121.1 (13.5)	23 (77)	7 (23)	96–139	117.2 (11.8)	41 (71)	17 (29)
Group 3	144–199	163 (19.6)	5 (56)	4 (44)	144–210	165 (17.5)	21 (64)	12 (36)
Total sample	72–199	117 (29.9)	37 (68)	17 (32)	72–210	120.1 (32.7)	88 (69)	39 (31)

[a] ID: Intellectual Disability

Table II: Kappa values for inter-rater and test-retest reliability for Child and Adolescent Intellectual Disability Screening Questionnaire items

Item		Inter-rater reliability				
	Number rating each item as yes or no (number)			Kappa value	*p* value	Agreement rating (from Landis & Koch[25])
		No	Yes			
Time (n = 137)	No	91	5	.709	<0.001	Substantial
	Yes	11	30			
Read (n = 139)	No	35	1	.625	<0.001	Substantial
	Yes	23	80			
Write (n = 138)	No	28	4	.26	<0.001	Fair
	Yes	51	55			
Laces (n = 138)	No	79	10	.833	<0.001	Almost perfect
	Yes	1	48			
				Test -retest reliability		
Time (n = 34)	No	23	0	1.00	<0.001	Almost perfect
	Yes	0	11			
Read (n = 32)	No	4	2	.59	.001	Moderate
	Yes	2	24			
Write (n = 31)	No	5	1	.708	<0.001	Substantial
	Yes	2	23			
Laces (n = 32)	No	21	0	.929	<0.001	Almost perfect
	Yes	1	10			

Contact with services (n = 31)	No	3	2	.611	0.001	Substantial
	Yes	1	25			
Support (n = 32)	No	25	2	.671	<0.001	Substantial
	Yes	1	4			
Friends (n = 30)	No	8	1	.981	<0.001	Almost perfect
	Yes	0	21			

Table III: CAIDS-Q[a] scores, FSIQ[b], and ABAS GAC[c] for each age group and the total sample

	ID[d]						Not ID					
	CAIDS-Q		FSIQ		ABAS GAC		CAIDS-Q		FSIQ		ABAS GAC	
	Range	Mean (SD)	Range	Mean (SD)	Range	Mean (SD)	Range	Mean (SD)	Range	Mean (SD)	Range	Mean (SD)
Group 1	14–33	25.4 (6.6)	41–68	54 (8.2)	50–69	61.1 (6.5)	17–100	56 (16.9)	62–117	86.9 (14.5)	56–110	79.2 (14.1)
Group 2	0–43	24.1 (13.5)	40–69	53.4 (9.7)	40–70	57.7 (9.0)	14–100	66.4 (18.6)	51–119	82.3 (13.1)	45–120	71 (13.9)
Group 3	14–50	33.1 (13.8)	40–68	48.3 (11.1)	47–70	55.2 (7.1)	43–100	74.3 (13.9)	56–126	77.8 (13.2)	54–107	73.5 (14.4)

Total sample	0–50	25.8 (12.2)	40–69	52.7 (9.6)	40–70	58.2 (8.2)	14–100	65.6 (18.2)	51–126	82.5 (13.9)	45–120	73.9 (14.4)

[a] CAIDS-Q: Child and Adolescent Intellectual Disability Screening Questionnaire

[b] FSIQ: Wechsler Intelligence Scales for Children – Fourth Edition (WISC IV) Full Scale IQ

[c] ABAS GAC: Adaptive Behaviour Assessment System General Adaptive Composite

[d] ID: Intellectual Disability

Table IV: Correlations between CAIDS-Q[a] total percentage score, FSIQ[b], and ABAS GAC[c]

	CAIDS-Q and FSIQ	CAIDS-Q and ABAS GAC	FSIQ and ABAS GAC
	r	r	r
Group 1	0.794	0.502	0.496
Group 2	0.731	0.527	0.486
Group 3	0.679	0.601	0.352
Total sample	0.621	0.482	0.474

[a] CAIDS-Q: Child and Adolescent Intellectual Disability Screening Questionnaire

[b] FSIQ: Wechsler Intelligence Scales for Children – Fourth Edition (WISC IV) Full Scale IQ

[c] ABAS GAC: Adaptive Behaviour Assessment System General Adaptive Composite