

Identifying children with intellectual disability

## **Facilitating the identification of intellectual disability in schools: a qualitative study of stakeholder views**

### **Authors**

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### **Abstract**

**Background:** Many children experience delayed or missed identification of an intellectual disability diagnosis, meaning that key opportunities for early educational intervention may be lost.

**Methods:** Semi-structured interviews were used to explore the views of teachers, parents, and clinicians (n = 22), about the use of the Child and Adolescent Intellectual Disability Screening Questionnaire (CAIDS-Q) and what could improve screening and identification of intellectual disability in schools. Thematic analysis was used to identify relevant themes.

**Results:** Three themes were identified: the need for, and role of, screening in the context of limited knowledge about intellectual disability; the impact of screening and subsequent identification of intellectual disability; and the context within which participants felt screening should take place in order to maximise its benefits.

**Conclusions:** The results confirmed the importance and benefits of timely identification of children with an intellectual disability and the positive role that screening might play in this.

**Keywords:** intellectual disability; Child and Adolescent Intellectual Disability Screening Questionnaire; schools; qualitative; screening; identification

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## **Introduction**

Intellectual disability is a neurodevelopmental condition, whereby the person experiences significant difficulties with their intellectual and adaptive functioning which were present before adulthood (The British Psychological Society [BPS], 2015, World Health Organisation, 2022). While people with an intellectual disability represent a heterogeneous group, common cognitive difficulties include working memory (Lifshitz, et al., 2016), and understanding abstract concepts, such as numbers and basic mathematics (Park et al., 2020), which are required for daily life. They are also more likely to face social exclusion and difficulties making friendships (Louw et al., 2020) to live in more socially deprived areas and to experience significant health inequities such as reduced life span and higher rates of death from avoidable causes, compared with the general population (Kings College London, 2021).

Identification of intellectual disability is, therefore, very important to ensure that the person's needs can be properly assessed, and that appropriate support and interventions are provided at an early stage (see Sigafos & Waddington, 2022). Early intervention can help to enhance the cognitive and social outcomes for younger children (Guralnick, 2017), while tailored educational interventions for students with intellectual disabilities have resulted in improvements in areas such as self-determination (Burke et al., 2020), a range of everyday skills (Sheppard & Unsworth, 2010), and abilities such as reading (Afacan et al., 2018) and mathematics (Spooner et al., 2019).

While the specifics of intervention approaches may vary, elements that are thought to be important are: reducing stressors for the child and family; involving family members, for example, supporting parents to develop responsive interaction styles with their children; and identifying and using learning contexts that help scaffold and facilitate the development of the children's skills (Smythe et al., 2021). Applied behaviour analytic techniques, such as

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task analysis, shaping, and the use of reinforcement are also increasingly being used to facilitate the structured teaching of skills (see Guralnick, & Bruder, 2019).

There are a range of targeted early intervention approaches offered in the United Kingdom. These includes PELICAN, which provides resources to help promote the emotional literacy of children; Early Positive Approaches to Support, which offers families group sessions covering relevant topics such as supporting communication, sleep, and development of skills; and Intensive Positive Behavioural Support Services, which provides multi-disciplinary support to children and young people who are at risk of hospital admission, most often due to aggression (see The University of Warwick, 2022).

In order to benefit from such interventions, however, the child's intellectual disability must be recognised in the first place. It is estimated that the prevalence rates for intellectual disability in children and young people aged up to 17 years are between 1.2% and 2% (Maenner et al., 2016; Maulik et al., 2011). The number of both children and adults identified as having an intellectual disability falls below this figure in the United Kingdom (UK), due to delayed or missed identification (e.g., Emerson & Glover, 2012; Simonoff et al., 2006). More recent research suggests that some children continue to have their intellectual disability overlooked, even when attending paediatric services (Delahunty et al., 2022). This means that key opportunities for intervention may have been lost.

A number of reasons have been proposed for why a child's intellectual disability may be delayed or missed. It is argued that professionals across education, health and third sector services carry a shared responsibility for identifying and supporting children and young people with an intellectual disability (Lenehan, 2017). The specific role that staff play may, however, differ according to their individual role and the overall remit of their service. If staff are uncertain about their responsibilities or feel they lack the training to properly fulfil them

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(Department for Education, 2020), the identification and support of children with an intellectual disability may suffer as a result. For example, educational provision for children with an intellectual disability comes under the remit of Special Educational Needs and Disability (SEND) in England and Additional Support for Learning (ASL) in Scotland. Special Educational Needs Coordinators (SENCOs) have a particular role in developing and coordinating support for children with an intellectual disability, however, such support is considered to be the responsibility of everyone in the school (Davies & Henderson, 2020).

Such support ranges from special schools, through specialist provision within mainstream schools to inclusive education. Meaningful inclusion has been defined as ‘a process of systemic reform embodying changes and modifications in content, teaching methods, approaches, structures, and strategies in education to overcome barriers with a vision serving to provide all students of the relevant age range with an equitable and participatory learning experience and environment that best corresponds to their requirements and preferences’ (Committee on the Rights of Persons with Disabilities, 2016, paragraph 11).

While there is only limited comparative research into the specific impact on people with an intellectual disability (Buchner et al., 2021), a systematic review of international research by Hehir and colleagues (2016) suggests that inclusive education can have benefits for all students in respect of their academic skills, e.g., literacy and numeracy, behaviour, and attendance, compared with those who have not experienced inclusion. The authors also reviewed research that included students with intellectual disability, and found that inclusive education could have positive outcomes, such as increased academic progress, faster reading speed, increased likelihood of engaging with further education after leaving secondary school and of living independently, compared with non-included peers.

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This research indicates the importance of meaningful inclusive education for children and young people with an intellectual disability. In order to benefit from an educational environment that maximises the academic and social learning of children with an intellectual disability, their intellectual disability needs to be recognised in the school context. Recent research suggests, however, that the processes for identifying children with SEND in England are failing. Hutchinson (2021) reported that the main predictor of a child being identified with SEND was the primary school that they attended, rather than their individual traits or behaviours. This may be because some teachers feel they have limited training and skills to identify and support children with SEND in general (Department for Education, 2020) and intellectual disability in particular (Rae et al., 2011). As a result, they may not understand the profile that a child with an intellectual disability may present with.

Even if a child is referred for diagnostic assessment, as the process requires assessment of the person's intellectual and adaptive functioning and developmental history, it can be time-consuming for both the person being assessed and the professional conducting it (BPS, 2015). These assessments also require specialist input, from psychologists with appropriate qualifications and experience (BPS, 2015), but access to such professionals, and in some cases to appropriate standardised assessments can be limited (see Tassé et al., 2019 for an overview). These factors can present barriers to assessment.

Different methods have been suggested to address these issues. Tassé et al. (2019) worked with experts in the field to develop behavioural indicators of intellectual and adaptive functioning. The authors note that these were designed to help inform clinical judgement about the likely presence and severity of intellectual disability when standardised assessments were not available. These indicators are likely to be beneficial to professionals working within a diagnostic context, however, there is a need for tools that are more appropriate for non-clinical staff to use.

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One such tool is the Child and Adolescent Intellectual Disability Screening Questionnaire (CAIDS-Q), which does not require the person completing it to have a specialist qualification or training. The CAIDS-Q is a short questionnaire, with seven questions that are answered 'yes' or 'no'. The score is converted to a percentage and children who fall below the cut-off are indicated as likely to have an intellectual disability. An online version of the CAIDS-Q is available at: <https://learningdisabilitymatters.co.uk/learning-disability-form/> Research in health care (McKenzie et al., 2012, 2019) and forensic settings (McKenzie et al., 2012a) indicates that the CAIDS-Q shows good sensitivity and specificity, is quick and easy to use, and has a number of benefits for children, families, and the services using it (McKenzie et al., 2019a). The screening tool is not designed to replace full assessment, but rather to indicate those children who are likely to have an intellectual disability and, therefore, benefit from further specialist assessment and support.

Teachers are very well placed to identify children who are likely to have an intellectual disability. This paper explores the views of parents, teachers, and clinicians about the use of the CAIDS-Q in schools to help identify children with an intellectual disability and support meaningful inclusion for them. It addresses the research question: what are the views of stakeholders about how the use of the Child and Adolescent Intellectual Disability Screening Questionnaire (CAIDS-Q) could improve screening, identification, and support of children with an intellectual disability in schools?

## **Method**

### ***Design***

A qualitative approach was employed, with data being gathered via individual semi-structured interviews. An interview schedule was used to guide the discussions, while

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allowing flexibility for topics which arose during the course of the interview to be discussed in more detail. The broad areas that were explored in the interviews included: the participants' understanding of what an intellectual disability was; associated difficulties and support needs; the reasons for, and role of, the screening tool in the early identification of people with an intellectual disability; the benefits and drawbacks of screening for different stakeholders, including the person being screened, teachers, parents, and wider services; the best ways to use the screening tool; and practical issues to consider when introducing the screening tool to schools. The transcribed interviews were analysed using thematic analysis (Braun & Clarke, 2006, 2021).

### *Participants*

A purposive sample of 22 participants, from across the UK, was recruited with the aim of including the views of key stakeholders who were involved in the process of identifying, supporting, and educating children with an intellectual disability. The inclusion criteria were that the participants had to be adults; provide informed consent, live or work in the UK and be from one of the following groups: teachers at mainstream or special schools, parents of children who had previously been screened using the CAIDS-Q; or clinical staff who had used the screening tool in practice.

The sample included 11 teachers (two males and nine females), only some of whom had experience of using the screening questionnaire, seven female clinical staff, all of whom had experience of using the screening questionnaire as part of their work, and four mothers whose children had all been screened and subsequently assessed as part of a previous project (McKenzie et al., 2019). Six of the teachers worked in a special school (3 of whom had previously worked in a mainstream school), and five currently worked in a mainstream school. Of the clinical staff, five were clinical psychologists/associates, one was a psychology



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assistant, and one was a paediatrician. The different groups of participants are indicated by their code prefix (see Table 1): Teachers at mainstream school (T), teachers at special school (ST), parents (P) and clinical staff/other staff (SP).

< Insert table 1 about here >

### ***Procedure***

The study obtained ethical approval from the first author's local university ethics committee (reference: 2741). All potential participants were initially contacted by email and provided with information about the study. To recruit teachers, two schools (one mainstream school and one special school) were contacted. As both schools agreed to participate, no further schools were contacted, and times to conduct face to face individual interviews, with those teachers who had agreed to take part, were arranged. The teachers were not known to the researchers. Those teachers who had not previously used the screening tool were given a copy of it prior to the interview, provided with information about it and given the opportunity to ask questions. The potential participants from the clinical staff group were invited to take part as they were known to have had experience of the screening tool in practice. The potential parent participants were also known, as they had agreed as part of a previous screening project to be contacted about future projects. As participants from the latter two groups were geographically dispersed, interviews were conducted by phone. The telephone was used as not all participants had access to technology that would allow online calls to be made.

The interviews included questions about the participants' understanding about intellectual disability, their views about the support needs of people with an intellectual disability; their perspective on early identification of intellectual disability, the actual/potential benefits and drawbacks of screening for intellectual disability, and any

practical issues to consider in relation to screening. Interviews lasted between 25 and 60 minutes and were digitally recorded and subsequently transcribed for analysis. All those taking part provided informed consent.

### ***Data analysis***

The data were analysed using thematic analysis, based on the guidance of Braun and Clarke (2006, 2021). The first and second authors independently read through all of the interviews to familiarise themselves with the data, before generating initial codes, by identifying potentially relevant aspects of the data. This included highlighting sections of text and grouping them together under preliminary categories. Both authors then worked together to discuss these initial codes and to categorise similar codes into potential themes and subthemes that were felt to best reflect the data and to address the research question. These themes and associated subthemes were then reviewed and refined by the two authors to ensure they were coherent and consistent. They were then integrated into their final format by the first author, who named them, and illustrated them using indicative quotes.

In order to maximise the rigour of the process, the guidance of Nowell et al. (2017) was followed. In addition, Yardley's (2008) quality criteria were used to guide the research process i.e., sensitivity, commitment and rigour, transparency and coherence of the data. Here, sensitivity to the context in which the research was taking place was addressed by taking account in the interview schedule and process of areas that had been identified in previous research as being important in screening, identifying, and supporting people with an intellectual disability in different contexts (Mckenzie et al., 2019a). This included awareness, knowledge, and acceptance of intellectual disability; the potential to identify those who were not previously known to have an intellectual disability and the possible impact of this; and the use of screening in practice and at different points in the assessment and support pathway.

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Commitment and rigor were considered in a number of ways. First, by identifying participants who were appropriate to the topic being addressed, i.e., parents, teachers, and clinicians with who either had experience of the screening questionnaire or who were able to provide their subjective views about its use in an educational context. Second, by sharing and discussing the final themes and associated sub-themes with members of the wider research team. This helped to ensure they were consistent with the content of the transcripts, evidenced by the sample quotes and reflective of the perspective of the participants. This also helped ensure transparency and coherence of the data. Reflexivity was promoted by having a research team with different experiences and perspectives and varying levels of previous involvement in research into the topic.

### *Researcher positions*

The research team comprised of four members who held a constructivist epistemological stance. Two of these were both applied psychologists and researchers who had been involved in the development of, or carrying out previous research into, the CAIDS-Q. As such, they did not conduct any of the interviews to ensure they did not influence participants' responses. A third member was an applied psychologist and the fourth was a psychology graduate. The latter two research team members had had no previous involvement with the CAIDS-Q.

## **Results**

Three themes were identified from the results. The first theme 'It's a big hole, a black hole' identifies the relationships between limited knowledge about intellectual disability, missed or delayed identification and the resulting impact on the support received by people with an intellectual disability and their families. The second theme, 'Small things that have a big impact' explores the impact of screening and subsequent identification of intellectual

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disability on children and families. The final theme, 'Is it a benefit to that person?' describes the context within which participants felt screening should take place. The themes and their associated subthemes are explored in more detail below.

***Theme 1: 'It's a big hole, a black hole'***

This theme explores the need for, and role of, screening for intellectual disability in the context of limited knowledge about what an intellectual disability is among some parents and professionals. It also addresses the importance of early identification and the consequences of missed and delayed identification for those with an intellectual disability. Three associated subthemes were identified.

*'Slip through the net'*

This subtheme explored the reasons why people with an intellectual disability may not be identified and, as a result, fail to be given the support they need in a timely way. One of the barriers to timely identification was that parents and teachers, particularly those working in mainstream schools, and other professionals, were not always confident about what an intellectual disability was: 'I honestly don't know...it is foreign to me...I don't have involvement with anyone with an intellectual disability so definitely need training.' (T8) and 'Before his diagnosis I was really ignorant, now it's amazing I didn't realise erm how big it effects, how common erm it is' (P1).

There was an awareness by some participants that people with an intellectual disability had cognitive difficulties, and difficulties with adaptive skills that could impact on many aspects of life:

Social interactions, a whole host of things like attending a doctor's appointment or a dental appointment. So, it's not just about being able to read and write, it is about using them skills elsewhere. (ST5).

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Other participants were less certain, describing intellectual disability as involving cognitive difficulties, but in the context of a 'natural' intelligence:

An intellectual disability would be anything that impacts the intelligence of the child, so they might be naturally intelligent, but have some difficulty in the process of understanding and communicating those types of things. (T9)

The lack of clarity about what an intellectual disability was could cause frustration for specialist services, when individuals were referred inappropriately as a result: 'We have had crazy referrals, like this person has an egg-shaped head, therefore, we need to speak to the learning disability team' (SP2). A further barrier to identification and support was that the needs of the child would be attributed to a reason other than intellectual disability: '...or he's just a naughty boy, but there might be other reasons for that, that could stem from an intellectual disability' (ST6). Similarly, if the child was quiet and well-behaved, he/she might be overlooked: 'They disguise it a little better... and they are always the ones I think of, the quieter children are the ones that could slip through the net' (ST6).

### *'Under the radar for a long period of time'*

This subtheme highlights the importance of early identification and support for people with an intellectual disability and their families, and the consequences of missed identification. Missed and delayed identification was seen to be detrimental to the long-term wellbeing of the person, because support was not given in a timely way: 'Arguably if they had had a more thorough assessment led by a screening tool earlier in life they would have the potential to have a much better quality of life' (SP3) and 'It's a big hole, a black hole and unfortunately some children are falling down this black hole and that's not right in this day and age' (ST5).

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A failure to identify an intellectual disability was seen to be one of the main challenges to the provision of appropriate support: 'One of the biggest barriers to children with any type of difficulty/disability like a learning disability is when they go under the radar for a long period of time' (ST5). Missed identification was thought to have a number of negative consequences for the child, particularly on the child's self-esteem: 'It can do your self-esteem...if you feel like at the moment everyone is doing something that you can't, that would be awful for them' (T10), and the development of behavioural difficulties:

If it isn't identified the children are often seen, because they can't engage in the lessons, they get bored and restless and start misbehaving and I mean, who can blame them? (ST2).

The detrimental impact on parents of not knowing about the child's intellectual disability was also highlighted: 'I felt lost for a year, maybe a year and a half until we got the result' (P1).

There was broad consensus amongst all participants of the need for timely identification, in order to avoid these potential negative consequences and ensure appropriate support was provided: 'So, it is really important that a diagnosis is picked up early to give the child whatever support they might need' (ST2). There was, however, some debate about how early this identification should take place, with most participants feeling it should occur as early as possible, in order to maximise the child's potential:

I think the longer you leave it the bigger these gaps become, so I think a lot of things can be picked up on early and support can be given from an early age to help them to keep up with the rest of their age range (T9).

*'It made people sit up and listen'*

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This subtheme describes the ways in which using an evidence-based screening tool helped parents and professionals to feel more confident in their opinion about whether the person had an intellectual disability or not. It also helped provide some clarity in situations where there was a sense that the person had difficulties, but the exact nature of them was unclear: 'I don't know but I did always suspect that there was something, not saying I expected it to be something like that, but I suspected, I always suspected' (P2). This often occurred in relation to learning difficulties, such as dyslexia: 'It could be dyslexia with the reading and writing, and yes...it could be an intellectual disability' (T7).

For many of the parents, the results of the CAIDS-Q confirmed the sense that they already had that their child had difficulties: 'It also confirmed that there was the intellectual disabilities as well, which we kind of thought he had anyway' (P1). This affirmation helped parents to advocate more strongly on behalf of their child: 'But it was really good to get [the diagnosis] as it gave us a real concrete of where he was and it made people sit up and listen' (P4) and remind others of their child's needs: 'I've got a better understanding with them [school]. If I find that they're forgetting or they're going off track I can challenge them as well' (P1).

The screening tool played a similar role for professionals, helping them to validate existing concerns about the person: 'So this would kind of be, the thing that clarifies your worries that you've already got?' (T8) and have confidence in identifying whether a person was likely to have an intellectual disability and to seek out more specialist services: '...much more confident in terms of referring on to learning disability services and much more confident at working out who may have a learning disability' (SP7). The results were also seen by some teachers as a way of approaching the topic with parents who were less aware of a child's difficulties:

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They get a bit defensive...that will be a really good tool to be able to show people, equally it could be powerful for school to do and be able to say this is where the child is now, this is why we are putting in these...different subtypes of support (ST6).

Or conversely to reassure parents that their child was unlikely to have an intellectual disability:

It might help a clinician to say look...this is reliable and valid screening tool and there's nothing here which would indicate intellectual disability...so it might be a good tool to help explain to parents why further assessment isn't warranted (SP3).

### ***Theme 2: 'Small things that have a big impact'***

The second theme explores the impact of screening and subsequent identification of intellectual disability on the children and families. This had two associated subthemes. 'He wasn't a failure he was improving' explores the educational impact of screening, 'When your child goes through it you also go through it' highlights the impact of screening on the wider family unit.

#### *'He wasn't a failure he was improving'*

This subtheme explores the impact of screening, and subsequent assessment on the understanding of the educational needs of the child and the types of additional support offered as a result. Many participants reported an increased understanding of the child's educational support needs. This led to expectations being adjusted accordingly:

After having the understanding with where he was and how his development rate was, we were able to continue things that, he wasn't a failure he was improving, it's just he's needing twice as long on that target rather than only giving him three months he needs six months (P1).



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This was seen as important in the context of schools being under pressure to meet certain educational targets: 'Treating them as individuals, not judging them because they are not meeting the national expected level and never will...they're not a statistic that's bringing our figures down, causing us to stress' (ST2).

Many of the teachers described the type of individualised support that was provided to children with an intellectual disability:

It's ok to break it down and to chunk it down into smaller levels of learning for our children and 5 minutes of really good quality learning is equally as good... where children can actually interact with the adults and the teachers (ST4).

Much of the additional support was school-based and was incorporated into the child's Individual Education Plan (IEP), leading to progress: 'I feel a lot more confident that he will reach his targets...I do think his IEP is a lot more tailored to him now than his first year' (P1) There was also greater consensus about the support that was needed:

Everybody had a different idea where he was at, what strategies we should be using, it caused conflicts between adults because we were disagreeing on how to, it helped everybody sing from one hymn sheet (P1).

The increased understanding of the child's needs also allowed for better planning around broader support needs, including clinical need: 'Yes...it would as it would give me further evidence to help me make a clinical decision as to whether it's appropriate' (SP3).

*'When your child goes through it you also go through it'*

This sub-theme describes the wider impact of screening on the child and family. In many cases, the increased understanding of the child and additional support that was offered had a positive impact beyond their learning. One important aspect of this, was the increased understanding of other people and changes in the way they viewed and approached the child:

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‘I would just say “Look, she’s got an intellectual disability” and immediately they’d talk to her differently, more appropriately’ (P3). This increased understanding could help improve family relationships: ‘It helped me explain to like erm wider family...so it really helped me get their understanding of where he was. And its’ improved relationships’ (P1). There were also improvements in the behaviour of some of the children: ‘He doesn’t shout out in class anymore which he used to do all the time, and when he gets anxious he talks constantly so he doesn’t do that as much’ (P4), and in the way that parents responded to behavioural challenges: ‘We’re able to spot things a lot quicker now, we’re able to intervene’ (P1).

These improvements in behaviour could also result in more options and activities for the child and respite for the family: ‘I’m now able to leave him [at grandparent’s house] because they’ve been able to adapt their routine with him to be comfortable enough to stay with him and enjoy his time there’ (P1).

### ***Theme 3: ‘Is it a benefit to that person?’***

The final theme describes the context within which participants felt screening should take place. This had four subthemes. The first, ‘You wouldn’t miss the ones that are sat at the back’ highlights the importance of screening taking place in a context, in terms of when, with whom, and how it should occur, that is likely to have the most benefit. The second, ‘The dots aren’t being joined up’ explores the requirements for effective screening to take place in a context where the results could be acted upon. The third, ‘There’s no test that is 100% right’ explores the participants’ views about the requirement for any screening tool to be accurate, valid and reliable. The final subtheme, ‘That’s quite a label’ discusses the perceived consequences of screening resulting in the child being labelled.

*‘You wouldn’t miss the ones that are sat at the back’*

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There was consensus among participants that screening should only be used if it was likely to be of some benefit, rather than just identifying that a person was likely to have an intellectual disability in isolation: 'I suppose the question is, is it a benefit to that person?' (SP5). This was often seen in the context of prompting further assessment of the person's needs: 'If you could screen, you could decide whether or not it is appropriate to conduct further assessments' (SP3).

There was some debate about at which stage in the child's development the screening tool should be used to maximise its benefit. The general view was that it could be used at an early stage to pick up initial signs of difficulty, usually from around age 6, as that was when the demands on the children were seen to increase: '6 upward... I think it's when we sit down and have more formalised education' (T9), and when any early signs of difficulty would be likely to be noticed. Screening was also seen as being helpful at later, transition stages, when the children had developed further: 'After 5 years or 10 years or whatever to get an update on their developmental progress, a review down the line' (P1), or were moving into high school: '...at that transition point, you would want to know and be making sure they have the right kinds of supports' (SP3).

In terms of which children should be offered screening, a number of participants felt that screening would be most appropriate for those about whom there were already concerns: 'I wouldn't do it on all of them, only the ones that I have concern over' (T7). Others, however, felt that the fact that the screening tool was quick and easy to use could mean that it could be used with all children to avoid overlooking the needs of children who were otherwise likely to be missed: 'It doesn't take long and I think if you did all the children then you wouldn't miss the ones that are sat at the back quiet who you think don't have a problem' (ST4). Screening everyone was also felt to be useful for providing a baseline against which subsequent child development could be measured: 'I think this would be really useful for a

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school to do on all their on-entry starts as a baseline, to say, is this someone we need to be keeping an eye on or not?' (ST5). The screening tool was seen as a way of providing additional, evidence-based information about the child's functioning '...the screening questionnaires...it's just a really good tool to give an indication (SP3).

### *'The dots aren't being joined up'*

Screening was considered to work best when used in the context of a clear pathway, to ensure that the results would be useful and acted on appropriately: 'I think if the service had a clear pathway... then I think I would formally use the screening tools more efficiently' (SP3). It was recognised that there was often a need for multi-disciplinary input to ensure the best assessment and support for the child: 'No one person has all the specialised knowledge, so everyone needs to join up' (ST3). Some participants, however, highlighted that navigating the different services could be challenging, particularly when there was poor communication between services: 'It just seems that the dots aren't being joined up here, from medical to educational to ourselves' (P3).

For some, having the results of the screening tool was helpful in facilitating access to the appropriate services: 'Yep, it has opened me up, introduced me to CAMHS... I was then given access to them through the school' (P1). For one parent, however, having her child's intellectual disability recognised as a result of screening, had not improved access to services, due to a lack of service coordination in the area: 'She's got the diagnosis which is great but nobody else seems to be talking or communicating, as each year goes on, she's needing things that she's not getting' (P3).

It was also recognised that screening was likely to have resource implications, that could act as a barrier to its use and/or the results of screening being acted on in terms of

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provision of the required support: 'Yeah, we didn't have any resources to put in extra support' (SP4) and:

You find out some information that you already don't know about the child, you have a moral duty to act on it...for some schools that can be quite scary, because who's going to do that and how on earth is the school going to fund it? (ST5).

On the other hand, it was recognised that providing additional support did not always require extensive resources or funding: 'It's really about having champions in the service who are prepared to do very simple actions afterwards like simplifying things they have to read, providing proper training, slotting them into the proper training program' (SP4).

Participants were generally clear that the screening tool was not a replacement for a comprehensive assessment: 'I suppose it is just a first step in the process and finding out what are the difficulties' (ST3), but instead highlighted the potential need for further assessment or helped to shape decisions: 'sort of a stepping-stone...it informs a decision it doesn't make it' (SP5). The importance of involving parents in the process was also highlighted: 'I think having a triangulation of data is really helpful because you have different points, so the staff member could do it, the parents could do it' (ST4).

*'There's no test that is 100% right'*

This sub-theme explores the participants' views about the importance of the properties of the screening tool in terms of accuracy, reliability, and validity. Participants described the need to ensure that the screening tool was accurate and brought more advantages than disadvantages: 'There's no test that is 100% right, and there's always a danger. Now my take on this is would the benefits outweigh the dangers?' (ST5).

A number of positive characteristics of the screening tool were highlighted - that it was not time-consuming: 'Is quite quick to administer and that's the whole point' (SP6), it

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was straightforward to use: 'It's easy to show someone how to use it' (SP7), had clear guidance: 'Yeah, it's 7 questions and they have strong guidance next to it so I think it would be really easy to implement.' (T7) and was fit for purpose: 'I think it did what it says on the tin, it did help us screen for those children.' (SP1).

On the other hand, the brevity of it meant that some participants felt some areas may have been missed: 'I think it was very succinct which made it useful at the time but also erm there may have been things that it didn't pinpoint' (SP1). There was also a suggestion that providing some broader training would help teachers to understand the purpose of screening better: 'I think general training for what this is used for and how it then feeds on to the process of how it's useful' (T9).

### *'That's quite a label'*

In terms of the social validity of the screening tool, the main concern about its use was in terms of labelling the child: 'That child has an intellectual disability, that's quite a label' (ST5), the potential associated stigma: 'I suppose some people might have concerns around the stigma of being labelled with a learning disability' (SP6) and that this might unnecessarily reduce expectations: '[If] said early that there was some kind of intellectual delay I would hate for them to never have ambition for that child' (ST6). Most participants, particularly parents however, viewed screening positively: 'I've not come across any personally [drawbacks], there may be that I'm not aware of but I've found it nothing but beneficial, to me' (P1) and as a means of getting assessment and support, rather than negative labelling: '...it actually doesn't label people because at the end of it all you can say is that this person might have a learning disability and he needs more support, and he needs proper assessment' (SP4).

## **Discussion**

## Identifying children with intellectual disability

The main purpose of screening for intellectual disability is to facilitate early identification and the provision of support which will improve the outcomes of children and young people. The study identified three main themes in relation to screening for intellectual disability in schools, which reflected these aims. The first explored some of the reasons why screening might be necessary, in the context of many people with an intellectual disability being overlooked by the systems that were designed to identify and support them (Emerson & Glover 2012; Delahunty et al., 2022; Hutchinson, 2021; Simonoff et al., 2006).

One key reason that was suggested for missed or delayed identification was limited knowledge about what an intellectual disability was. Previous research has also found that those who should be well-placed to identify people with additional support needs, including intellectual disability have limited knowledge, including teachers (Department for Education, 2020; Rae et al., 2011) and those working in specialist health services (Delahunty et al., 2022, McKenzie et al., 2019). Research with parents indicates that, while the process is not always easy for them, they value receiving a diagnosis for their child, particularly at the stage when developmental concerns first arise (Makela et al., 2009). The diagnosis can help parents to develop an increased understanding of the strengths and needs of their child, access intervention and support (Watson et al., 2011), increase awareness of, and empathy towards, others with disabilities (Marsh et al., 2020), and offer validation for parents in relation to their child's characteristics and behaviour (Makela et al., 2009).

As well as, increasing awareness about intellectual disability (McKenzie et al., 2019a), the use the CAIDS-Q in a variety of service contexts including forensic, paediatric, intellectual disability, and child and adolescent mental health services, has helped to identify those who were previously not known to have an intellectual disability (see McKenzie et al., 2021 for an overview). As such, it may also offer a way to reduce missed identification of intellectual disability in schools.

Recent UK guidance has emphasised the importance of teachers having an understanding of children with special educational needs in order to provide them with effective support (Davies & Henderson, 2020), however many feel they lack the knowledge (Department for Education, 2020) and confidence (Rae et al., 2011) to do so effectively. Screening was identified by participants as a way of providing some clarity and validating concerns about a child's progress. It provided parents and others with greater confidence and certainty, for example when referring on to clinical services or advocating on behalf of a child. Research in other settings has also found that the results of screening are felt to lend authority and credibility to requests for support from external organisations (McKenzie et al., 2019b).

There was consensus that early identification of intellectual disability was important, and that screening could play an important role in facilitating this. The majority felt that screening should be carried out with children about whom there were some concerns. The specificity of the CAIDS-Q is high (McKenzie et al., 2019), however, screening all children in a class is likely to result in a number of false positives i.e., children who are identified by the screening tool as having an intellectual disability when they do not.

An important aim of screening is that it should ultimately have a positive impact (McKenzie & Murray, 2022). The effects of timely and targeted support are highlighted by research which shows that early intervention programmes and targeted educational input can have benefits for the child and family. Using approaches such as involving and supporting family members (Smythe et al., 2021), and using applied behaviour analytic techniques (see Guralnick, & Bruder, 2019) to shape the learning environment and scaffold learning can improve outcomes. These include better social and cognitive outcomes (Guralnick, 2017), increased self-determination (Burke et al., 2020) and improved academic abilities such as mathematics and reading (Afacan et al., 2018; Spooner et al., 2019).



The research participants in the present study outlined a number of potential and actual benefits of screening, including speeding up the diagnostic process, increasing the understanding of the person and his/her needs, and the provision of extra and /or more tailored educational and other support. These benefits are consistent with those found when the CAIDS-Q was used in paediatric services (McKenzie et al., 2019a) and in other health and forensic services in the UK and internationally (see McKenzie et al., 2021)

Most participants stressed that, in order to be of benefit, screening should occur in a context that facilitates assessment and support, does not stigmatise the child, or place excessive demands on resources. Previous research indicates that very few people consider screening to be stigmatising and find the CAIDS-Q accurate, quick, and easy to use (e.g., McKenzie et al., 2019a, 2021). In terms of the context within which the CAIDS-Q might be used, the ‘Assess, Plan, Do, Review’ approach is adopted, as part of the SEND Code of Practice (Department for Education and Department of Health, 2015), by many schools in the UK. This offers a framework whereby information is gathered from multiple stakeholders about the child and is integrated to develop evidence-based support strategies, which are implemented and subsequently reviewed to establish their effectiveness (Davies & Henderson, 2020). The use of the CAIDS-Q would appear to fit well within the ‘Assess’ stage of this existing framework.

The study did have limitations. The participants were included because they reflected parents and staff who were or could potentially be involved in the education and support people with an intellectual disability, some of whom had direct experience of using the CAIDS-Q, and/or represented involvement in different aspects of the screening pathway. They did, however, form a somewhat heterogeneous group as a result. Despite this, themes were identified which reflected a broad consensus among participants. A related limitation is that those who agreed to be interviewed may have had a particular interest in screening and as

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such, their views may not be reflective of the wider population. As with other qualitative research, we do not claim that our results are generalisable to all teachers, parents, and clinicians, but instead offer a detailed insight into the views and experiences of some. A further limitation is that some participants were interviewed in person, while others were interviewed by telephone. This may have influenced the results, particularly as the latter method does not allow non-verbal cues to be picked up by the interviewer. Finally, an important theme related to the context within which screening was conducted. The educational system in the UK is likely to differ from that in other countries. The broad message that screening should be beneficial, be part of a clear assessment and support pathway and not place excessive demands on those involved in the process is, however, applicable more widely.

## **Conclusion**

The study identified the potential importance and benefits of timely identification of children with an intellectual disability and the positive role that offering screening in schools might play in this. Teachers are very well placed to identify children who are experiencing difficulties and the study suggests that the CAIDS-Q could offer an acceptable, evidence-based way of identifying whether these children are likely to have an intellectual disability and would benefit from further assessment and additional educational support.

## References

- Afacan, K., Wilkerson, K.L., & Ruppard, A.L. (2017). Multicomponent reading interventions for students with intellectual disability. *Remedial and Special Education, 39*(4), 229-242.
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology, 3*(2), 77-101.
- Braun, V., & Clarke, V. (2021): One size fits all? What counts as quality practice in (reflexive) thematic analysis? *Qualitative Research in Psychology, 18*(3), 328-352.
- Burke, K.M., Raley, S.K., Shogren, K.A., Hagiwara, M., Mumbardó-Adam, C., Uyanik, H...Behrens, S. (2020). A meta-analysis of interventions to promote self-determination for students with disabilities. *Remedial and Special Education, 41*(3), 176–188
- Buchner, T., Shevlin, M., Donovan, M-A., Gercke, M., Goll, H., Šiška, J... Vlachou, A. (2021). Same Progress for All? Inclusive Education, the United Nations Convention on the Rights of Persons with Disabilities and Students with Intellectual Disability in European Countries. *Journal of Policy and Practice in Intellectual Disabilities, 18*(1), 7-22.
- Committee on the Rights of Persons with Disabilities. (2016). *General comment No. 4 on the right to inclusive education*. CRPD/C/GC/4. Available at:  
<https://www.ohchr.org/Documents/HRBodies/CRPD/GC/RighttoEducation/CRPD-C-GC-4.doc>

Identifying children with intellectual disability

Davies, K. & Henderson, P. (2020). *Special Educational Needs in Mainstream Schools: Guidance Report*. UK: Educational Endowment Fund.

Delahunty, L., O'Hare, A., Marryat, L., Stewart, T.M., McKenzie, K., Murray, G.C., & Kaza, N. (2022). Short Report: Exploring the extent to which Intellectual Disability is undiagnosed within children attending developmental paediatric clinics. *Research in Developmental Disabilities, 131*, 104359.

Department for Education (2020). *The School Snapshot Survey: Summer 2019- Support for Pupils*. Available at:  
[https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/885697/SSS\\_Summer19\\_Support\\_for\\_Pupils.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/885697/SSS_Summer19_Support_for_Pupils.pdf)

Department for Education and Department of Health (2015). *Special Educational Needs and Disability Code of Practice: 0 to 25 years*. Available at:  
<https://www.gov.uk/government/publications/send-code-of-practice-0-to-25>

Emerson, E., & Glover, G. (2012). The ‘‘transition cliff’’ in the administrative prevalence of learning disabilities in England. *Tizard Learning Disability Review, 17*(3),139-143.

Guralnick, M.J. (2017). Early intervention for children with intellectual disabilities: an update. *Journal of Applied Research in Intellectual Disabilities, 30*, 211–219.

Guralnick, M.J., & Bruder, M.B. (2019). Early intervention. In J. L. Matson (Ed.). *Handbook of Intellectual Disabilities – Integrating Theory, Research, and Practice* (pp. 717-742). Springer Publishing.

Hehir, T., Grindal, T., Freeman, B., Lamoreau, R., Borquaye, Y., & Burke, S (2016). *A Summary of the Evidence on Inclusive Education*. Brazil: Instituto Alana Rua.

Identifying children with intellectual disability

Available from [https://alana.org.br/wp-content/uploads/2016/12/A\\_Summary\\_of\\_the\\_evidence\\_on\\_inclusive\\_education.pdf](https://alana.org.br/wp-content/uploads/2016/12/A_Summary_of_the_evidence_on_inclusive_education.pdf)

Hutchinson, J. (2021). *Identifying Pupils with Special Educational Needs and Disabilities*.

Education Policy Institute. Available at: [https://epi.org.uk/wp-content/uploads/2021/03/SEND-Indentification\\_2021-EPI.pdf](https://epi.org.uk/wp-content/uploads/2021/03/SEND-Indentification_2021-EPI.pdf)

Kings College London (2021). *LeDer Annual Report: Learning from lives and deaths*

– *People with a learning disability and autistic people*. Kings College: London

Lenehan, C. (2017). *These are our children*. Available at:

[https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/585376/Lenehan\\_Review\\_Report.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/585376/Lenehan_Review_Report.pdf)

Lifshitz, H., Kilberg, E., & Vakil, E. (2016). Working memory studies among individuals

with intellectual disability: An integrative research review. *Research in Developmental Disabilities, 59*, 147-165.

Louw, J.S., Kirkpatrick, B., & Leader, G. (2020). Enhancing social inclusion of young adults

with intellectual disabilities: A systematic review of original empirical studies. *Journal of Applied Research in Intellectual Disabilities, 33*(5), 793-807.

Maenner, M. J., Blumberg, S. J., Kogan, M. D., Christensen, D., Yeargin-Allsopp, M., &

Schieve, L. A. (2016). Prevalence of cerebral palsy and intellectual disability among children identified in two US National Surveys, 2011–2013. *Annals of Epidemiology, 26*(3), 222–226.

Makela, N.L., Birch, P.H., Friedman, J.M., Marra, C.A. (2009). Parental perceived value of a

diagnosis for intellectual disability (ID): A qualitative comparison of families with

Identifying children with intellectual disability

and without a diagnosis for their child's ID. *American Journal of Medical Genetics*, 149A(11), 2393-2402.

Marsh, L., Brown, M., & McCann, E. (2020). The views and experiences of fathers regarding their young child's intellectual and developmental disability diagnosis: Findings from a qualitative study. *Journal of Clinical Nursing*, 29(17-18), 3373-3381.

Maulik, P. K., Mascarenhas, M. N., Mathers, C. D., Dua, T., & Saxena, S. (2011). Prevalence of intellectual disability: A meta-analysis of population-based studies. *Research in Developmental Disabilities*, 32(2), 419–436.

McKenzie, K., & Murray, K.R. (2022). Exploring the validity of screening for learning disability – using the Wilson-Jungner screening programme criteria. *Learning Disability Practice*. doi: 10.7748/ldp.2022.e2205

McKenzie, K., Murray, G.C., Murray, A.L., Delahunty, L., Hutton, L., Murray, K., O'Hare, A. (2019). Child and Adolescent Intellectual Disability Screening Questionnaire to identify children with intellectual disability. *Developmental Medicine and Child Neurology*, 61(4), 444-450.

McKenzie, K., Murray, A.L., Murray, G.C., & Martin, R. (2021). The use of an impact questionnaire as a framework to evaluate the impact of research on policy and practice: screening questionnaires for intellectual disability. *Research Evaluation*, 30(2), 141–153.

Mckenzie, K., Murray, G., Murray, A., Martin, R., Tanfield, Y., Delahunty, L., Hutton, L., Murray, K. R., & O'Hare, A. (2019a). Screening for intellectual disability with the Child and Adolescent Intellectual Screening Questionnaire: A modified Delphi approach. *Developmental Medicine & Child Neurology*, 61(8), 979–983.

## Identifying children with intellectual disability

- McKenzie, K., Murray, G.C., Wilson, H., & Delahunty, L. (2019b). Homelessness – ‘It will crumble men’: the views of staff and service users about facilitating the identification and support of people with an intellectual disability in homeless services. *Health and Social Care in the Community*, 27(4), e514-e521
- McKenzie, K., Paxton, D., Michie, A., Murray, G., Murray, A., & Curtis, J. (2012a). Screening with young offenders with an intellectual disability. *Journal of Forensic Psychiatry & Psychology*, 23(5–6), 676–688.
- McKenzie, K., Paxton, D., Murray, G., Milanesi, P., & Murray, A. L. (2012). The evaluation of a screening tool for children with an intellectual disability: The Child and Adolescent Intellectual Disability Screening Questionnaire. *Research in Developmental Disabilities*, 33(4), 1068–1075.
- Nowell, L.S., Norris, J.M., White, D.E., & Moules, N.J. (2017). Thematic Analysis: Striving to meet the trustworthiness criteria. *International Journal of Qualitative Methods*, 16, 1–13
- Park, J., Bouck, E.C., & Josol, C.K. (2020). Maintenance in mathematics for individuals with intellectual disability: A systematic review of literature. *Research in Developmental Disabilities*, 105, 103751
- Rae, H., McKenzie, K., & Murray, G.C. (2011) Teaching staff knowledge, attributions and confidence in relation to working with children with an intellectual disability and challenging behaviour. *British Journal of Learning Disabilities*, 39, 295-301.
- Sheppard, L., & Unsworth, C. (2010). Developing skills in everyday activities and self-determination in adolescents with intellectual and developmental disabilities. *Remedial and Special Education*, 32(5), 393-405

## Identifying children with intellectual disability

Simonoff, E., Pickles, A., Chadwick, O., Gringras, P., Wood, N., Higgins, S., ... & Moore, A.

(2006). The Croydon Assessment of Learning Study: prevalence and educational identification of mild mental retardation. *Journal of Child Psychology and Psychiatry*, 47(8), 828-839.

Sigafoos, J. & Waddington, H., (2022). Early assessment and intervention: Introduction to the Special Issue. *Advances in Neurodevelopmental Disorders* 6, 367–368.

Smythe, T., Zuurmond, M., Tann, C.J., Gladstone, M., & Kuper, H. (2021). Early intervention for children with developmental disabilities in low and middle-income countries – the case for action. *International Health*, (13)3, 222–231.

Spooner, F., Root, J.R., Saunders, A.F., & Browder, D.M. (2019). An updated evidence-based practice review on teaching mathematics to students with moderate and severe developmental disabilities. *Remedial and Special Education*, 40(3), 150–165.

Tassé, M.J., Balboni, G., Navas, P., Luckasson, R., Nygren, M.A., Belacchi, C...Kogan, C.S. (2019). Developing behavioural indicators for intellectual functioning and adaptive behaviour for ICD-11 disorders of intellectual development. *Journal of Intellectual Disability Research*, 63(5), 386–407.

The British Psychological Society (2015). *Guidance on the Assessment and Diagnosis of Intellectual Disabilities in Adulthood*. The British Psychological Society: Leicester

The University of Warwick (2022). *Investing in Early Intervention*. Available at:

<https://cerebra.org.uk/download/investing-in-early-intervention/>

Watson, S.L., Hayes, S.A., & Radford-Paz, E. (2011). “Diagnose me Please!”: A review of research about the journey and initial impact of parents seeking a diagnosis of



Identifying children with intellectual disability

developmental disability for their child. *International Review of Research in Developmental Disabilities*, 41, 31-71.

World Health Organization. (2022). *ICD-11: International Classification of Diseases (11th revision)*. <https://icd.who.int/>

Yardley, L. (2008). Demonstrating validity in qualitative psychology. In J. A. Smith (Ed.), *Qualitative Psychology: A Practical Guide to Research Methods* (pp. 235–251). London: Sage.

**Table 1**

**Participant code and information**

<b>Code</b>	<b>Information</b>
ST1	Teacher in special school. Has previously worked in mainstream school.
ST2	Teacher in special school
ST3	Teacher in special school. Has previously worked in mainstream school.
ST4	Teacher in special school
ST5	Teacher in special school. Has previously worked in mainstream school.
ST6	Teacher in special school
T7	Teacher in a mainstream school
T8	Teacher in a mainstream school
T9	Teacher in a mainstream school
T10	Teacher in a mainstream school
T11	Teacher in a mainstream school
SP1	Psychology assistant, working in a clinical psychology service
SP2	Clinical psychologist working in an intellectual disability service
SP3	Applied Psychologist working a child and adolescent mental health service
SP4	Clinical Psychologist/researcher working in the field of intellectual disability
SP5	Clinical Psychologist working in an intellectual disability service
SP6	Paediatrician
SP7	Clinical Psychologist working in an intellectual disability service
P1	Parent of child diagnosed with intellectual disability as a result of screening
P2	Parent of child who was screened (no intellectual disability)
P3	Parent of child diagnosed with intellectual disability as a result of screening

