Screening for Intellectual Disability in Children

Screening for Intellectual Disability in Children:

A Review of the Literature

Keywords: Children, Intellectual Disability, Screening Tools

Abstract

Background: Early identification of possible intellectual disability can help children and families access appropriate services and support more quickly. There has been an increasing interest in the use of screening tools for this purpose. This paper reviews the literature in relation to such tools.

Methods: A literature search was carried out for English language papers from 1990 to 2009 using a range of databases. Secondary searches were carried out from references of relevant papers.

Results: Only one paper was identified which examined the ability of an assessment to specifically identify children with a potential intellectual disability, however, no information was provided about sensitivity, specificity or cut-off points.

Conclusions: There is not, as yet, a screening tool which can reliably identify children with a probable intellectual disability. Further research in this area is needed.

Background

There are a number of difficulties in accurately estimating the number of children who have an intellectual disability, due to differences in the assessments, methodologies (Roeleveld et al., 1997) and terminology used as well as in the populations studied (Fryers, 1997), however, worldwide prevalence rates for mild and severe intellectual disability are estimated to be 3% and 0.38% respectively (Roeleveld et al., 1997). Intellectual disability is defined as: a significant impairment of intellectual functioning (i.e., an IQ of less than 70); a significant impairment in two or more areas of daily living and onset before age 18 (World Health Organisation, 1992). It is diagnosed by a standardised assessment of cognitive and adaptive functioning, as well as a developmental history (American Association of Intellectual and Developmental Disabilities, (AAIDD), 2009).

By definition, all children with an intellectual disability will have significant difficulties with cognitive and adaptive functioning. They also have a number of additional care needs, including increased mental health problems (Emerson and Hatton, 2007), increased rates of severe sleep disorders (Richdale et al., 2000) and challenging behaviours (Baker et al., 2003), physical health problems (Courtman & Mumby, 2008) and higher rates of co-morbidity e.g. Autistic Spectrum Disorder (Croen et al., 2002). Many are thought to need higher levels of care and more educational support than children without intellectual disability (Simonoff et al., 2006). In addition, parents of children with an intellectual disability are more likely to experience mental health difficulties and stress than other parents (Fidler et al., 2000).

There are, therefore, a number of reasons to accurately identify those children who have an intellectual disability and differentiate them from children who may have other cognitive

difficulties, such as specific learning difficulties. The identification of intellectual disability in children can, however, be problematic, especially for those with significant intellectual impairment (Hamilton, 2006; Simonoff et al., 2006). This means that the timing and process of diagnosis is extremely variable (Quine & Rutter, 1994) and may not occur until the individual is in his/her teens (Simonoff et al., 2006) or has reached adulthood (Hamilton, 2006). This can result in a delay in meeting the support needs of the child (McGinty & Fish, 1992) and such delays have been found to be one of the main factors related to stress and dissatisfaction with service provision in parents of children with an intellectual disability (Carmichael et al., 1999). In addition, delays in identification and intervention can have a negative impact on the child's learning, communication and adaptive skills (Herbert, 2006; Chadwick et al., 2005) and can result in others failing to understand the child's difficulties and behaviour (Goodman & Linn, 2003).

The difficulty in identifying children with an intellectual disability at an early stage may be due to a number of factors. Firstly, there is limited knowledge about what an intellectual disability is on the part of education (Rae et al., 2011), health (McKenzie et al., 2000) and social care staff (Williams et al., 2009) and, in the U.K., frequent confusion between the terms 'learning disability' and 'learning difficulty' (Hames & Welsh, 2002). This is likely to be exacerbated by the fact that different countries use different terminology to describe the same group of people. In the UK, the term 'learning disability' is used, while many European countries and until recently, the US adopt the term 'mental retardation' (AAIDD, 2009; Reid, 1997). 'Intellectual disability' has now been adopted by the AAIDD as the term in the U.S. and is used by academics and clinicians in a number of other countries (Reid, 1997).

Secondly, the diagnosis of intellectual disability requires an assessment of intellectual and adaptive functioning, as well as a developmental history. These assessments are time-consuming to complete and the former must be carried out by, or under the supervision of, qualified professionals, normally applied psychologists (Goldstein et al., 2004; British Psychological Society (BPS), 2001). There has, therefore, been an increasing impetus to find alternative ways of identifying children who may have an intellectual disability at an early stage. This has led to an interest in the use of screening tools.

Screening tools may be used for a number of different purposes. Clinical services may screen as a way of increasing efficiency through reducing waiting times and guiding appropriate referrals (Bailey et al., 2005; BPS, 2003). Early identification can also inform early interventions (Guralnick, 2005). Education services may wish to predict which children are at risk for educational difficulties and identify appropriate support for them within the school setting (Sonnander, 2000). Researchers may use screening tools to provide a quick and easy means of identifying particular population samples (Charman et al., 2007) while forensic services may wish to identify potentially vulnerable adolescents with an intellectual disability in the criminal justice system (Ford et al., 2008; Talbot & Riley, 2007). At a broader level, screening tools may be used in an attempt to meet government policies and targets which require early and accurate identification of children with intellectual disabilities (Sonnander, 2000; Glascoe & Byrne, 1993) or to provide estimated prevalence rates of intellectual and other disabilities in certain populations or countries (Mirza et al., 2008; Xie et al., 2008). As screening tools may be used for a range of different purposes, it might be expected no one tool can meet these differing needs (Rafoth, 1997).

For any screening tool to be useful and effective it has to meet a number of basic criteria. As one of the main aims of screening is to reduce the amount of time involved in assessment, it has to be quick and easy to use and appropriate to the group for which it was designed (Glascoe, 2005). In order to identify the target population, it must also have strong psychometric properties including standardisation, reliability, validity, with acceptable values of 70-80% in relation to sensitivity and 80% for specificity (Rafoth, 1997; Sonnander, 2000; Glascoe, 2005). These values may, however, vary depending on the purpose of the screening tool and the relative costs of false negatives and false positives (Charman et al., 2007). Additional calculations of positive and negative predictive powers may also be included (Glascoe, 2005). The psychometric properties of any given tool will depend on the characteristics of the population being screened (Charman et al., 2007), for example the predictive values of a test are influenced by the prevalence of the condition in the population being screened, although these values are seldom reported (Camp, 2006). Table 1 below summarises the psychometric characteristics required of a good screening tool.

INSERT TABLE 1 HERE

The development and use of screening tools is, however, not straightforward. The rapid development of young children's cognitive and social processes makes very early identification of intellectual disability difficult (Bornholt et al., 2004) and screening carried out with infants during the first 24 months of life has low predictive validity in relation to later cognitive functioning (Sonnander, 2000). Developmental changes with age also present challenges for screening in older children. Different skills are acquired at different ages and are influenced by a range of environmental factors, therefore, developmental problems which

were not apparent at one age may become obvious at another (Glascoe, 2005), meaning that a screening tool must be developmentally sensitive.

There are also a number of ethical issues that have to be considered when using screening tools. Sonnander (2000) notes that early identification is only advantageous if there are adequate resources to subsequently meet the needs of children who are found to have an intellectual disability. In addition, as a screening tool can only give an indication of whether an individual falls into a particular category or not, there must be the facility to provide proper diagnostic assessment when required. A screening tool that produces a number of false positives may result in services being stretched by requests for diagnostic assessment or to provide input to those who do not fall within their remit. It is also likely to cause unnecessary stress for the families of those children who are incorrectly classified as having an intellectual disability. Conversely, false negatives may result in children who require additional support, failing to receive it.

Aim

The aim of this paper is to address the question: how well do screening tools specifically identify children with an intellectual disability?

Method

Search strategy

A literature search was carried out with the keywords 'screening' or 'assessment' tool or test + 'intellectual disability', 'mental retardation' or 'intellectual disability' + 'child* using the following databases: Ovid, PsycINFO, Global Health, EMBASE, AMED, CINAHL, Medline, Web of Science, World CAT . A search was also carried out using the Cochrane database.

Secondary searches were carried out from references of relevant papers. The search was restricted to articles in the English language and from 1990 to early 2009. The exclusion term 'learning difficulty' was used. For the purposes of the study, children were defined as being aged up to 18 years.

The initial search produced over 3000 potential papers. Once duplicates and papers which were clearly irrelevant were excluded, approximately 600 remained. To refine the search further, a number of additional exclusion criteria were applied. Papers were excluded if the screening was based on short forms of intellectual or neuropsychological assessments, as such screening would still require to be carried out by appropriately qualified professionals, such as applied psychologists (Goldstein et al., 2004; BPS, 2001). In addition, research with adults with an intellectual disability shows that many do not have a uniform cognitive profile (Murray et al., 2002), suggesting that short-forms of intellectual assessments may be inaccurate with this group. Using such short-forms with children may have similar limitations. Papers which screened for specific learning difficulties or general school performance and those relating to genetic or medical prenatal or postnatal screening were also excluded. Papers relating to screening for very young children (under age 2) were excluded due to previous reviews which have indicated that such screening is poor at predicting future intellectual functioning (Bornholt et al., 2004, Sonnander, 2000). An additional condition which was applied was that the minimum criterion for concurrent validity was the comparison of the screening tool with a valid, reliable and standardised assessment of intellectual functioning. Finally, papers which reported on screening tools which were designed primarily for adults, but included some adolescents in the standardisation sample were also excluded (e.g. Ford et al., 2008).

A detailed examination of the remaining 26 papers indicated two main limitations in terms of their applicability to the screening of children with an intellectual disability. One group of studies reported on screening tools for a range of disabilities e.g. physical, intellectual, hearing which were used to provide, amongst other things, estimated prevalence rates of intellectual disability in certain countries and populations. The classification was subsequently confirmed or otherwise by diagnostic assessment, but no information was provided that allows the psychometric properties of the tool to be calculated specifically in relation to identifying intellectual disability (Xie et al., 2008; Mirza et al., 2008; Bashir et al., 2002; Christianson et al., 2002;). These papers were, therefore subsequently excluded from the review.

A second group of studies reported on the reliability and validity of screening tools in large, heterogeneous populations such as children at risk for low IQ (Russell et al., 2002, McIntosh, 1999: McIntosh et al., 2000; Montgomery et al., 1999, Andrews et al., 1995) and poor educational attainment (Scott et al., 1998; Scarr et al., 1994) or children with general disabilities (Chopra et al., 1999, Thorburn et al., 1992, Zaman et al., 1990), general cognitive impairment (Besson & Labbe, 1997) or developmental delay (Heo et al, 2008, Rydz et al., 2006, Walsh et al., 2007, Billard et al., 2002, Lenkarski et al., 2001, Sonnander & Claesson, 1999, Leppert et al., 1998, Deuel, 1998; Glascoe & Byre, 1993). Some researchers reported on the identification of children with intellectual disabilities within the wider group being screened, however, the screening tools used were not developed specifically for this purpose. It was, therefore, unclear to what extent they could differentiate between children with an intellectual disability and children with other cognitive, behavioural or social difficulties. These papers were also excluded from further detailed review.

A final quality indicator was then applied: that the study had a sufficient sample size to achieve statistical power. Camp (2006) also notes that small sample sizes in screening tools can lead to unreliable results due to the large confidence intervals involved. This led to the exclusion of a small pilot study of the child learning disability screening tool (CLDSQ) (McKenzie et al., 2008) developed from the adult version (LDSQ, McKenzie & Paxton, 2006). The CLDSQ was specifically developed to identify children with probable intellectual disability and had concurrent validity based on a clinical assessment of all three diagnostic criteria for an intellectual disability, however, it was based on a small sample size of 33 children.

The one remaining paper was by Simonoff et al. (2006) and utilised the Cognitive Abilities Test (CAT) (Thorndike & Hagen, 1986) as a screening tool. The CAT was originally designed to assess reasoning abilities linked with academic success, with the aim of identifying talented children or children at risk, however, it was included in this review as Simonoff et al. (2006) utilised it specifically as a screening tool for mild intellectual disability. The authors note, however, that due to a lack of a standardised short form of CAT, items for their study were selected based on face validity and from the psychometric data provided for the complete test: they included verbal and non-verbal subtests but omitted the mathematical subtests.

The study included 2726 children between 12-13 years old from 15 schools (including schools for children with moderate learning disability, physical disability and emotional and behavioural disorders. The children completed the CAT individually, in small groups or in their class or year group. Scores were age-corrected allowing children to be identified according to risk of mild intellectual disability. A follow-up study of 204 children (80

children categorised as high risk, 60 moderate risk and 64 low risk) involved in depth assessment, including a range of cognitive, psychological and attainment assessments, information from parents and a medical examination. Intellectual functioning was assessed using 9 subtests from the WISC-III (Wechsler, 1992). Data were adjusted in 3 stages to account for non-participants, the sampling design and differences between the number of children who were recorded on the school rolls and those who were estimated as being resident in the area from the local census.

The authors found a correlation of 0.76 between total CAT scores and WISC-III full Scale IQ scores with the highest correlation of 0.77 being found between Verbal IQ and CAT total score. They conclude that CAT is an effective screening tool for intellectual disability, but unfortunately fail to provide sensitivity and specificity values or cut-off scores for the test which would indicate intellectual disability in this sample. The CAT was also only administered to children in the 12-13 age group and its developmental sensitivity as a screening tool for children with an intellectual disability is unknown. The authors do not specifically state the length of time it took to complete the short form of the CAT, however they note that the time period allowed to complete the test was extended, enabling it to be completed in two school class periods. This suggests that the version of the CAT used by Simonoff et al. (2006) may not be much quicker to administer than standardised intellectual assessments.

The paper reports on a comprehensive and interesting study and the authors were thorough in accounting for potential sources of bias in the data, for example in relation to non-participants, however, it is unclear what the impact was of using a non-standardised short form of the CAT as a screening tool and a shortened form of the WISC III (Wechsler, 1992)

to assess intellectual functioning. In addition, both of these assessments have been revised since the study was carried out, meaning that research using the updated tools would be required before firm conclusions could be drawn about the utility of the CAT as a screening tool for children with an intellectual disability.

Conclusion

Accurate and timely diagnosis of intellectual disability has clear benefits in terms of accessing support and services, but it is estimated that only 15-20% of professionals such as paediatricians and doctors use formal screening measures (Dobrez et al., 2001, Hamilton, 2006), partly due to a lack of agreement on which screening tool to use (Dobrez et al., 2001). This lack of agreement is understandable, given that no single screening tool which was reviewed was shown to be sufficiently valid or reliable for use with children with an intellectual disability.

The review did, however, highlight a number of areas that future researchers need to address if developing a screening tool. Importantly, the tool must serve the purpose for which it was designed. In some developing countries or areas where service provision is limited, the purpose of the screening tool may be to provide an initial indication of the number of children with a range of different disabilities, rather than focusing on children with intellectual disabilities per se (e.g. Thorburn et al., 1992; Zaman et al., 1990). In countries where service provision for children with an intellectual disability is well established, screening tools are likely to serve a range of different purposes including early identification. In these circumstances, for maximum utility, the screening tool should be designed specifically to identify children with an intellectual disability and differentiate these children from other groups, rather than including them in a large heterogeneous sample such as children with

developmental disabilities, low IQ or educational difficulties. The concurrent validity of the

tool should be, at minimum, measured against the diagnostic criteria of intellectual disability,

which in turn should be assessed by a valid, reliable, individually administered assessment of

intellectual functioning. The tool needs to be developmentally sensitive and to have sufficient

participants in each age band to ensure that there are not fluctuations in sensitivity and

specificity due to children at different ages having scores with vastly different standard

deviations (Camp, 2006). Similarly the overall number of participants must be sufficient to

ensure the study has statistical power. Data should be provided that allows the tool to be

assessed in terms of the criteria of a good screening tool (Charman et al., 2007; Camp, 2006;

Glascoe, 2005) and the likely prevalence of intellectual disability in the population being

screened should be accounted for to ensure an accurate measure of the positive predictive

power of the tool.

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Table 1: Psychometric properties of a good screening tool

Standardisation	The screening tool should be standardised against a large population of children from different geographical areas, socioeconomic and ethnic backgrounds, age and gender. This sets the 'normative' base for a screening tool. Ideally, the screening tool should be standardised for each target population that the screen claims to identify.
Reliability	A screening tool should give similar results for an individual each time it is administered irrespective of time intervals or who is administering or scoring the test.
Validity	This ensures that the screening tool is measuring what it is set out to measure. There are a number of different forms of validity including: • Face validity i.e. the extent to which the screening tool looks like it is measuring what it sets out to measure • Discriminative validity i.e. the extent to which a tool can correctly predict which group a person belongs to; • Concurrent validity i.e. the degree to which the scores of a screening test agree with the scores of an established intellectual assessment an adaptive behaviour assessment.
Sensitivity	This is the probability that a true positive (in this case a child with an intellectual disability) will be correctly identified as such by the screening tool. It is found by dividing the number of true positives by the number of true positives added to the number of false negatives [$Sn = TP / (TP + FN)$].

Specificity	This is the probability that a true negative (in this case a child who does not have an intellectual disability) will be correctly identified as such. It is found by dividing the number of true negatives by the number of true negatives added to the number of false positives [Sp = TN / (TN + FP)].
Positive predictive value	This identifies the proportion of those who are identified as positive by the test in question (in this case as having an intellectual disability) who are correctly identified as such. This is given by the number of true positives divided by the total number of positives (both true and false positives) given by the test [PVV=TP/(TP+FP)].
Negative predictive value	This identifies the proportion of those who are identified as negative by the test in question (in this case as not having an intellectual disability) who are correctly identified as such. This is given by the number of true negatives divided by the total number of negatives (both true and false negatives) given by the test [NPP=TN/(TN+FN)].

Screening for Intellectual Disability in Children