A review of measures used in the screening, assessment and diagnosis of dementia in people with an intellectual disability

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Abstract

Background: The increasing number of individuals with an intellectual disability (ID) who are at risk of developing dementia highlights the need to use measures with strong psychometric properties as part of the screening, assessment and diagnostic process

Method: Searches were made of clinical and good practice guidelines and English language journal articles sourced from Proquest, Web of Science, and Scopus databases (up to July 2017) for tools which were designed or adapted for the purpose of helping to diagnose dementia in people with ID.

Results: Based on a detailed review of 81 articles and guidelines, we identified 22 relevant tools (12 cognitive, 10 behaviour). These were reviewed in terms of their psychometric properties

Conclusions: A number of tools were found to be available for use with people with ID, however, few were specifically standardised for this purpose which also had comprehensive information about reliability and validity

The longer lifespan of people with an intellectual disability (ID) means that an increasing number are at risk of developing dementia, most commonly Alzheimer's disease (AD; McCarron, McCallion, Fahey-McCarthy, Connaire, & Dunn-Lane, 2010). This is particularly true for people with Down syndrome (DS), who not only have a greatly increased prevalence of AD compared to the general population but are at risk of developing it at a much younger age (Lott & Dierssen, 2010; Strydom et al., 2009). Research suggests that individuals with ID experience a somewhat different course and progression of the disease, with the initial signs tending to be in behaviour and personality rather than in memory (see Torr, Strydom, Patti, & Jokinen, 2010). The rate of decline is much faster, with the average duration from diagnosis to death being six years (Prasher & Krishnan, 1993).

This highlights the need for accurate screening, assessment, and diagnosis of dementia in order to ensure that those who are affected receive appropriate care and support as early as possible. There are, however, a number of challenges to achieving this. These include the variability in the degree of ID prior to the onset of dementia and limited information about the way in which this impacts on the course of the disease (Carr, 2000; Strydom et al., 2009). While a number of assessments are available (see Zeilinger, Stiehl, & Weber, 2013, for an overview), only some of those have been standardised for use with people with ID. A related issue is that administration of neuropsychological tests can be difficult or impossible with those who have a severe or profound ID (e.g. Crayton, Oliver, Holland, Bradbury, & Hall, 1998). In such cases there may be reliance on informant information, however high turnover of paid carers may mean that reliable information about the person's functioning over a longer period of time may not be available (Crayton & Oliver, 1993). If baseline information is missing, then it is challenging to determine an accurate onset and course of dementia. This can also add to the difficulties involved in differentiating the

symptoms that are due to dementia from those associated with the individual's ID, the normal ageing processes, or health conditions that may have symptoms that mimic those of dementia (McKenzie, Baxter, Paxton, & Murray, 2002).

Both the British Psychological Society (BPS; 2015) and National Institute for Health and Care Excellence (2016) provide guidance on the assessment and diagnosis of dementia in people with ID and identify a number of assessments that can be used in this process. Zeilinger et al. (2013) also review available assessments but do not evaluate them in respect of their psychometric properties. Perhaps unsurprisingly, given the issues with assessment highlighted previously, no single assessment is recommended. The BPS (2015) note that a specific recommendation cannot be made until further research comparing the efficacy of different assessments is made.

This paper aims to review the range of tools designed or adapted for the purpose of helping to diagnose dementia in people with ID in order to help clinicians choose the best assessment for their purpose and particular individual being assessed. The review splits these tools into those that primarily measure cognitive functioning and those that primarily measure behaviour. A brief overview of each tool is given, along with an outline of their psychometric properties..

Search Strategy

The first stage of the search for instruments involved consulting guidance documents (e.g. BPS, 2015; Das, Mishra, Davison, & Naglieri, 1995; Gangadharan, Devapriam, & Bhaumik, 2009) to identify key tools that are used, or are recommended for use, for screening, assessment, and diagnosis of dementia in people with ID. Searches using the terms outlined with 'AND' and 'OR' statements were conducted in the Proquest,Web of Science, and Scopus databases. These searches were restricted to journal publications in the English language, with the keywords found in the title, abstract, or keyword sections (see table 1).

<Insert Table 1>

A general search was also conducted using combinations of the key terms: ‘intellectual/learning’, ‘disability’, ‘dementia’, ‘Alzheimer’s disease’, ‘Down syndrome’, ‘assessment’, ‘screening’, and ‘measures’. Measures that are specifically designed to assess and screen cognitive change (such as the Wechsler scales) but are not designed to assess or screen for dementia were not reviewed. Where the authors were unable to source manuals for particular assessments and no other published information was available, this is noted. Some papers were excluded if the published information was limited or if the papers referred to measures as part of a battery which were covered individually elsewhere in the review. Some measures have been included even where published research is limited because they are new versions of measures that have previously been used in the assessment and diagnosis of dementia. Further information on some of the measures included in the review is available via text books (e.g. Prasher, 2018). Readers may wish to consult such sources for more detailed information in relation to specific measures.

The initial search yielded 1,496 results (Proquest = 421; Web of Science = 892; Scopus = 183). This was reduced to 1,203 when duplicates were removed. Screening of titles and abstracts reduced this further to 57 articles. These were read in detail and 38 were retained. An inspection of reference lists and additional focused searches relating to each identified measure provided an additional 43 articles. In total, 81 articles were included in the review. The measures included in the review were independently rated by the three authors and any disagreements were resolved through discussion.

<Insert Figure 1>

Cognitive measures

Cambridge Examination for Mental Disorders of the Elderly modified for use assessing people with Down syndrome (Ball et al., 2004)

This is a version of the Cambridge Examination for Mental Disorders of the Elderly (CAMDEX) by Ball et al. (2004) modified for use assessing people with Down syndrome (CAMDEX-DS). The adaptation shifts the focus to the individual's decline from their best level of functioning and excludes items that have ceiling or floor effects. Although designed explicitly to detect AD in people with DS, it is thought likely to be appropriate for use with the wider population of people with ID (Ball et al., 2004).

Reliability.

Inter-rater reliability. This was based on the correlation between the CAMDEX-DS scores and a psychiatrist's assessment for 20 individuals. The majority (91%) of items fell in the near perfect range (Kappa > 0.8), with the remaining items showing substantial agreement (Kappa > 0.6; Ball et al., 2004).

Validity. The CAMDEX-DS was designed to identify those showing a high degree of cognitive decline indicative of AD, measured as a reduction in scores of 1 standard deviation (*SD*). However, of those who showed a decline greater than 1 *SD*, none were diagnosed with AD (Ball et al., 2004).

The measure was also used to diagnose dementia in a group of people with mild to severe ID (Holland, Hon, Huppert, Stevens, & Watson, 1998). The extent of decline due to dementia increased with age, but no effect of severity of ID on age of dementia onset was found. The measure was also considered to have good face validity.

Predictive validity. Those with a diagnosis of dementia at baseline assessment were significantly ($p < 0.005$) more likely to show decline than those without a diagnosis at baseline assessment. Those with a diagnosis showed eight times more deterioration

throughout the six years of observation (Holland & Ball, 2009). The CAMDEX-DS also showed high sensitivity (0.88) and specificity (0.94) values (Ball et al., 2004).

No diagnoses made using the CAMDEX-DS were reversed at the six year follow-up, indicating it to be a valid diagnostic tool (Ball et al., 2004).

Cambridge Cognitive Examination modified for use in a group with Down syndrome (Hon, Huppert, Holland, & Watson, 1999)

The Cambridge Cognitive Examination modified for use in a group with Down syndrome (CAMCOG-DS) is adapted from the Cambridge Cognitive Examination (CAMCOG; Huppert, Brayne, Gill, Paykel, & Beardsall, 1995) and the Severe Impairment Battery (SIB; O'Caoimh, Clune, & Molloy, 2013). Since its original publication, some tests of executive function have been deemed too difficult for the target group and were removed from the tool. In all, there are seven subscales. The tool was designed to detect dementia (no specific form noted) in people with DS.

Reliability. No information specific to the CAMCOG-DS was found.

Validity.

Predictive validity. Ball et al. (2006) examined changes in scores over a five year period in five groups: those showing changes in personality/behaviour, those with dementia frontal type, those with dementia Alzheimer's type, those with no diagnosis aged 50 years and above, and those with no diagnosis aged under 50. The overall score on the CAMCOG-DS showed significant differences between all groups. The first four groups all showed significantly greater decline, depicted by total score, compared to the last group.

On the executive function subscale, both the over and under 50 groups with no diagnosis showed no significant difference between the start and end of the five year period; whilst the individuals in the other groups showed significant decline. On the memory subscale, individuals in the under 50 no diagnosis group, personality/behaviour change group,

and the dementia frontal type group all showed no significant difference; whilst those in the over 50 no diagnosis group and the dementia Alzheimer's type group both showed significant decline (Ball et al., 2006). Crucially, only those in the dementia Alzheimer's type group showed decline in both areas of cognitive function.

When decline was standardised, a significant difference in executive function and memory was seen in the group with AD, with the greatest decline on the memory measure. No other group showed a difference between executive function and memory scores.

Further research by Benejam et al. (2014) found that scores at baseline were related to severity of ID, with people with a moderate ID scoring higher than those with mild ID. These results were not related to gender or age. Throughout follow-up over a three year period, ten patients developed AD and decline in their CAMCOG-DS scores was observed. The earliest affected domains were memory, language, and visual perception. In healthy participants, no change in CAMCOG-DS scores was observed.

Concurrent validity. It was found the CAMCOG-DS correlated highly with scores on the Mini-Mental State Examination (MMSE; Hon et al., 1999). Correlation remained high when similar items on each scale were omitted (Hon et al., 1999).

Dementia Questionnaire for People with Learning Disabilities (Evenhuis, 1992; Evenhuis, Kengen, & Eurlings, 2009)

The Dementia Questionnaire for People with Learning Disabilities (DLD), formerly known as the Dementia Questionnaire for Persons with Mental Retardation (DMR), was designed for detection of dementia in people with ID (Thompson, 2001). It was originally designed for detection of different forms of dementia, but as AD is the most common, it has been primarily validated in people with this condition (Evenhuis, Kengen, & Eurlings, 2009). It is completed by someone who knows the person well. The questionnaire consists of eight subscales, split into two main categories: cognitive scores (SCS) and social scores (SOS;

Thompson, 2001). It is suggested that higher scores in both categories, in subsequent administrations over time, may be indicative of dementia (Evenhuis et al., 2009).

Reliability.

Inter-rater reliability. Evenhuis et al. (2009) calculated the inter-rater reliability according to each subscale. All but the behaviour and disturbance subscale, which had a value of 0.44, had correlations above 0.68. The authors attribute the low inter-rater reliability of this subscale to one pair of raters. Walker, MacBryer, Jones, and Law (2014) assessed the inter-rater agreement between two carers of 26 people with DS, who completed the DLD separately. The authors found 'good' agreement, defined as a correlation of 0.80 or above, for only 15% of carer pairs. Overall, agreement was better for less able people with DS. In addition, five of the 26 rater pairs had a discrepancy of 7+ points on the SCS and/or a difference of 5+ points on the SOS. The authors concluded that this discrepancy, which Evenhuis et al. (2009) suggested as being indicative of dementia, sheds doubt on how reliably changes over time can be interpreted as such when differences in scores may be due to poor inter-rater reliability.

Validity.

Predictive validity. Evenhuis et al. (2009) reported that people with dementia had significantly higher scores compared to those without, suggesting the measure is sensitive to dementia. Similarly, Oliver, Kalsy, McQuillan, and Hall (2011) found more impairment on the DMR in a group of individuals with DS and dementia compared to a group without. Jordens, Evenhuis, and Janssen (1997), however, compared scores on the DLD between people with ID and people with ID and dementia and found no difference between the groups. Those with high functioning DS performed worse on the scale.

When compared to the Test for Severe Impairment, the DLD was found to be more sensitive tracking changes through time, detecting deterioration five years before a diagnosis of dementia (McCarron, McCallion, Reilly, & Mulryan, 2013).

Sensitivity and specificity. This varies for people with ID and dementia, from sensitivity of 57% to 100% and specificity of 39% to 85%. Values are higher for those with DS and AD, with values for sensitivity being between 83% and 100% and specificity between 80% to 81% (Evenhuis, 1996).

Evenhuis et al. (2009) suggested that diagnosis of types of dementia other than AD may be less accurate but, as data were based on small numbers of people in these subgroups, the authors emphasised that this conclusion was speculative. Prasher (1997) found the DLD to have sensitivity of 91.5% and specificity of 47%, with a false positive rate of 38.5% when used with individuals with DS. When the marking criteria were changed, such that both cognitive and social scores had to be higher than the threshold, sensitivity was reduced to 82%, specificity increased to 82%, and the false positive rate was 18.5%. When the measure was used longitudinally, sensitivity was found to be 60% and specificity 67%.

Concurrent validity. The DLD was found to correlate highly with the Dementia Scale for DS (G-DSDS; Deb & Braganza, 1999), the American Association of Mental Deficiency Adaptive Behavior Scale (AAMD ABS; Kirk, Hick, & Laraway, 2006), the Vineland Adaptive Behaviour Scale (VABS; Sparrow, Cicchetti, & Saulnier, 2016), and the Assessment for Adults with Developmental Disabilities (AADS; Oliver, Kalsy, McQuillan, & Hall, 2011). It has been shown to correlate well with a battery of tests which includes the VABS II and the British Picture Vocabulary Scale (Poveda & Broxholme, 2016). However, it has been shown to correlate poorly with the Checklist for Symptoms with Dementia (CLD) and with expert opinion (Hoekman & Maaskant, 2002).

Deb and Braganza (1999) noted that the DLD may not be an accurate measure of dementia in people with severe ID. Boada et al. (2008) also used the DLD and found greater impairment in the group with more severe ID, whilst finding no difference by group using the Severe Impairment Battery (SIB) and the Mini-Mental State Examination (MMSE).

Kirk et al.(2006) found that scores on the DLD did not differ by gender and were comparable in those with DS and ID.

Down Syndrome Mental Status Examination (Haxby, 1989)

The Down Syndrome Mental Status Examination (DSMSE) was designed for the study of age related differences in people with DS. It is a measure of neuropsychological function which can be subdivided into a number of different areas.

Reliability. Information not found.

Validity.

Predictive validity. Haxby (1989) found the measure significantly discriminated between three groups: younger adults, older non-dementing adults, and older adults with dementia (type not specified). However, the range of scores between the latter groups overlap and adults with dementia have a greater average age than those without dementia, suggesting that the scores may be influenced by age.

A further study by McCarron, Gill, Lawlor, and Begley (2002) found, in participants with a moderate ID, that those without a diagnosis of dementia performed better than those with a diagnosis of dementia (type not specified). No difference was found on DSMSE scores for those with and without dementia in participants with severe ID, due to a floor effect. More recently, a longitudinal study by McCarron et al. (2013) found the DSMSE could detect deterioration one year prior to a diagnosis of dementia.

Cognitive Scale for Down Syndrome (Startin, Rodger, Fodor-Wynne, Hamburg, & Strydom, 2016)

The Cognitive Scale for Down Syndrome (CS-DS) is a recently developed measure designed for, and validated with, people with DS. It was developed with a wide participant group (British sample), taking into account people with diverse abilities, cognitive decline, and dementia. It is an informant questionnaire with three domains: memory, executive function, and language. It has minimal floor and ceiling effects. The authors have suggested that it may be useful for tracking decline over time and may be more sensitive to detecting early changes than other assessments, as it focuses on changes in cognitive abilities, rather than a wide variety of changes.

Reliability. The CS-DS has shown very good test-retest and inter-rater reliability, and good internal consistency (Startin et al., 2016). Inter-rater reliability between a researcher and an informant, regardless of the type of informant (paid carer or family member), showed no significant difference.

Validity.

Predictive validity. Controlling for age and baseline level of ID, the scores of adults with significant cognitive decline were significantly lower on the scale than adults with no cognitive decline (Startin et al., 2016).

Severe Impairment Battery (Saxton, McGonicle, Swihart, & Boller, 1993)

The Severe Impairment Battery (SIB) is an assessment of cognitive function designed for persons who are severely demented. Although not originally designed for use with people with ID, many studies have used the SIB and its implementation as an assessment of cognitive functioning has been assessed with people with DS (Witts & Elders, 1998). The assessment can be broken into nine main areas of function and cut-offs for scores for severe impairment are documented, but only for typically developing samples (Witts & Elders, 1998).

Reliability. The SIB has shown a high test-retest reliability in a group of people with ID without dementia (Witts & Elders, 1998).

Validity. The battery shows a strong significant correlation with the Dementia Questionnaire for People with Learning Disabilities (DLD) in a group of people with DS, but no dementia (Hutchinson & Oakes, 2011), and good concurrent validity when compared with the Vineland Adaptive Behaviour Scales (VABS). This was when used both to track decline 12-24 months after baseline assessment (McKenzie, Harte, Patrick, Matheson, & Murray, 2002) and when controlling for age (Witts & Elders, 1998).

By contrast, Boada and colleagues (2008) found no differences in scores on either the SIB or the Mini-Mental State Examination (MMSE) between people with different levels of severity of ID. This indicates that these assessments may not be accurately assessing differences in these groups. Research by Dick, Doran, Phelan, and Lott (2016) found no difference on any of the SIB subscales between people with DS and dementia and typically developing people with AD when the functional abilities of the two groups were controlled for. The authors suggest that the SIB was not appropriate for use with people with more severe impairment.

Rivermead Behavioural Memory Test (Wilson, Cockburn, & Baddeley, 2008)

The Rivermead Behavioural Memory Test (third edition; RBMT-3) consists of 14 subtests and is used for assessing memory changes associated with a range of conditions, such as dementia and normal ageing. It was not designed specifically for people with ID, but has been researched with this population to a limited degree.

Reliability. All subtests of the RBMT-3 have a high inter-rater reliability (0.9 or higher; Wilson et al., 2008).

Validity. The information below does not refer to people with ID unless specified.

The measure has been normed in groups with stroke, traumatic brain injury, dementia, and alcohol-related diseases and revealed significant differences between groups for screening score (van Balen, Westzaan, & Mulder, 1996). A relationship has also been found between the RBMT (Brazil version) and the memory subscale of the Cambridge Cognition Examination (CAMCOG), the CAMCOG total score, and the Mini-Mental State Examination (MMSE; Yassuda et al., 2010). The measure was found to have good sensitivity, specificity, and positive and negative predictive values when discriminating between individuals with AD and a control group. Individuals with brain damage also scored significantly lower than controls on the RBMT (Wilson, Cockburn, Baddeley, & Hiorns, 1989).

There is only limited research in relation to people with ID. A version adapted for children (RBMT-C) has been reportedly used with people with DS. This appears to show an absence of floor and ceiling effects (Wilson & Ivani-Chalian, 1995), suggesting it may be appropriate for use with this group. Later research by Hon, Huppert, Holland, and Watson (1998) confirmed few floor effects were seen unless the individual had a severe or profound ID or already had AD.

Dementia Rating Scale (Mattis, 1988)

The Dementia Rating Scale (DRS) is a scale designed to detect dementia in the typically developing population. It consists of five subscales: attention, initiation and perseveration, construction, conceptualisation, and memory. The administration can be shortened, as within each subscale the most difficult items come first and if the person answers these items correctly they do not complete subsequent tasks (PAR, n.d.).The DRS was not specifically designed for people with ID.

The information below applies to people *without* ID, unless specified.

Reliability.

Test-retest reliability. Overall, this was found to be high (total = 0.93; Schmidt, Mattis, Adams, & Nestor, 2005).

Validity.

Sensitivity and specificity. Using the cut-off point defined in the test, the sensitivity and specificity were shown to be quite good (sensitivity = 0.80; specificity = 0.68). When including only patients with dementia, this was shown to be perfect (sensitivity = 1.00; specificity = 1.00; Matteau et al., 2011).

Concurrent validity. This has been shown to be quite good, with a moderate-high correlation with the Mini-Mental State Examination (MMSE; $r = 0.65$, $p = 0.000$) and a moderate correlation with age ($r = 0.44$, $p = 0.000$; Matteau et al., 2011).

In a study with participants with DS, age and diagnosis showed no significant effect on the overall score but the interaction between the two was significant. Scores showed that the pattern of results was significantly different for the young DS group and the old DS group. The interaction shows that the baseline IQ and DRS scores in the young group were not correlated, whereas in the older group they were (Das, Divis, Alexander, Parrila, & Naglieri, 1995).

Test for Severe Impairment (Albert & Cohen, 1992)

The Test for Severe Impairment (TSI) is designed to assess neurological functioning and is split into six sections. It is not designed for use with people with ID or specifically for the detection of dementia, but it has been used this way. Very few of the questions require a verbal response and it is reported to take less than ten minutes to complete (Albert & Cohen, 1992).

Reliability. The initial study indicated items were grouped together well and that the measure had good internal and test-retest reliability (Albert & Cohen, 1992). This research did not include people with ID.

This measure shows mixed results in relation to inter-rater reliability when used with people with ID and no dementia diagnosis, with a smaller group of male participants showing a far higher inter-rater reliability than a larger female group. When inter-rater reliability is viewed in terms of level of intellectual impairment, it is similar and relatively high for those with both moderate and severe ID. A similar pattern is seen with test-retest reliability. Numbers in this sample were, however, small (Cosgrave et al., 1998).

Validity. Originally, the TSI was correlated with the Mini-Mental State Examination (MMSE), showing a strong correlation in a sample of people with cognitive impairment, including with dementia (Albert & Cohen, 1992). Further analysis has shown that convergent validity is quite good in a group of people with ID but no diagnosis of dementia and, overall, is higher in a group of people with ID and dementia (Cosgrave et al., 1998). In a longitudinal study, it was shown to detect deterioration one year prior to a diagnosis of dementia (McCarron et al., 2013).

The test is not influenced by education or age, however this was only shown in a sample of people without ID (Albert & Cohen, 1992).

Mini-Mental State Examination (Folstein, Folstein, & McHugh, 1975)

The Mini-Mental State Examination (MMSE) is a short test, split into eight subscales. It is designed to assess cognitive functioning and is completed with the person under investigation. The MMSE has not been validated for use with people with ID and very limited information on its validity in this group could be found. While some researchers have used the MMSE with people with ID (Kálmán et al., 1997), other research suggests it may be of limited utility with this group due to some people being unable to complete the assessment (Deb & Braganza, 1999).

The information below applies to people *without* ID, unless specified.

Reliability. The reported reliability of the MMSE is mixed. Inter-rater reliability is reported as being above 0.65, while estimates of internal consistency range from 0.31 to 0.96. Test-retest reliability is good, falling between 0.80 and 0.95 for intervals less than two months, and above 0.80 for intervals between one and two years (Strauss, Sherman, & Spreen, 2006).

Validity. The sensitivity of the test has been found to vary from 0.49 (Ganguli et al., 1993) to 0.92 (Heun, Papassotiropoulos, & Jennssen, 1998), while specificity was 0.92 or above.

There are reported correlations with other cognitive measures, such as the Blessed Orientation-Memory-Concentration test (BOMC), the Dementia Rating Scale (DRS), the clock drawing task, the Spanish versions of the Mental Status Questionnaire (S-MSQ), the Information-Memory-Concentration test (S-IMC), and the Orientation-Memory-Concentration test (S-OMC), all which are reported by Strauss et al. (2006).

An assessment of people with ID and dementia showed no significant difference on the MMSE when comparing participants with and without dementia. However, the MMSE correlated significantly with the Severe Impairment Battery (SIB) and Dementia Questionnaire for People with Learning Disabilities (DLD; Boada et al., 2008). Research found the MMSE to correlate with IQ in people with ID with a range of conditions, including dementia, but not with those participants without ID (Myers, 1987).

Neurotrax Computerized Moderate to Severe Impairment Battery (Simon, Doniger, Dimant, & Dwolatzky, 2007)

The Neurotrax Computerized Moderate to Severe Impairment Battery was originally designed as a brief comprehensive assessment to be used longitudinally to track and monitor cognitive impairment in older adults (Simon et al., 2007). It has since been assessed for use in people with DS who are developing AD (Gutman, Moskovic, & Jeret, 2016).

Reliability.

Test-retest reliability. Tested every six months over 18 months, no significant change through time was reported (Gutman et al., 2016).

Validity. Gutman et al. (2016) found no changes in scores over time in people with DS or ID but concluded the measure can be used to track change over time. It was considered to be unsuitable for individuals with severe levels of ID when used with people with DS.

Prudhoe Cognitive Function Test (Kay et al., 2003)

The Prudhoe Cognitive Function Test (PCFT) is designed as a direct test of cognitive function for individuals with ID. It is designed to measure change through time and there are three versions, one long and two short. It takes approximately 35 minutes to complete the long-form.

Reliability.

Internal consistency. The PCFT shows a high Cronbach's alpha (0.94; Kay et al., 2003).

Interrater reliability. There are very high intra-class correlations for the measure; raters were not specialists (0.99 – 0.98; Margallo-Lana et al., 2003).

Test-retest reliability. A very high test-retest reliability has been reported (0.99; Margallo-Lana et al., 2003).

Validity. There was no correlation with age and no effect of gender found, however differences were found between people with more and less severe ID (Kay et al., 2003).

Concurrent validity. The PCFT correlates highly with the American Association of Mental Deficiency Adaptive Behaviour Scale (AAMD ABS; Kay et al., 2003). Verbal and performance subscales of the Kaufman Brief Intelligence Test (K-BIT) correlate well with the PCFT (0.85 and 0.78). The two short versions correlate very highly with the long form (0.97 and 0.98; Tyrer et al., 2010).

<Insert Table 2>

Behaviour Measures

Vineland Adaptive Behaviour Scales (Sparrow, Cicchetti, & Saulnier, 2016)

The Vineland Adaptive Behaviour Scales (third edition; VABS-III) measures adaptive behaviour throughout the lifespan. There are multiple versions available – a long and short form in three different versions: Interview, Parent/Caregiver, and Teacher. There are five main domains, each of which contains two to three subscales. The VABS-III manual shows percentages of special education groups in the normative sample, broadly in line percentage-wise with the numbers seen in the US population. The VABS-III has been validated with some people with ID, though not specifically with those with dementia.

Reliability. The reliability information provided in the VABS-III manual is not specific to people with ID, however they were included within the larger sample. All forms of the VABS-III showed good internal consistency, standard error, test-retest, and inter-rater reliability.

Validity. Means and standard deviations for groups of people with ID (separated by IQ) are reported, as are standard differences between this group and matched controls. These are provided for the Interview, Parent/Caregiver, and Teacher forms.

Concurrent validity. This is not reported specifically for people with ID, but for the group as a whole. The Interview form shows a moderate correlation with the VABS-II. The Parent/Caregiver form shows a moderate correlation with the VABS-II and correlations with the Bayley Scales of Infant and Toddler Development (third edition; Bayley-III) are reported as 'moderately high'. The Teacher form shows moderate to high correlations with the VABS-II. Correlations between different versions of the VABS-III are average.

Adaptive Behaviour Assessment System (Harrison & Oakland, 2015)

The Adaptive Behaviour Assessment System (third edition; ABAS-3) measures adaptive behaviour throughout the lifespan. It has two parent/primary caregiver forms (ages 0-5 and ages 5-21), two teacher forms (ages 2-5 and ages 5-21), and an adult form (ages 16-89). It measures adaptive skills in a number of areas which are combined to provide four overall domain scores: General Adaptive Composite, Conceptual, Social, and Practical. The ABAS is used for a number of reasons, such as the diagnosis of ID, monitoring interventions, and identifying functional limitations, including in those with dementia.

Standardisation. The US standardisation sample was based on 7,737 forms completed for 4,500 individuals who were aged 0 to 89 years old. Most of the standardisation sample was typically developing individuals, with only very small numbers of participants with ID being included in any of the reliability and validity studies. Twenty-one pre-school aged children, 28 school age children and adolescents, and 11 children aged 4-5 with ID were included in the sample. No information about adults with ID was evident.

Reliability. The reliability statistics provided in the ABAS-3 manual were largely derived from general population samples, rather than specifically people with ID. The test-retest scores were similar for adults rated by self (N = 36) and adults rated by others (N = 37), with correlations ranging between 0.75 and 0.95. Inter-rater reliability scores were adequate to high (N = 88), ranging from correlations of between 0.74 and 0.87. Across a large sample (N = 831), the cross form consistency was adequate, with scores ranging between 0.64 and 0.75.

Validity. Little information is provided in the ABAS-3 manual about the validity of the assessment, with much of the data presented being correlations with older versions of the ABAS, conducted with children, or in small samples. While some studies were conducted with adult clinical groups, only scores, rather than information on validity, are presented.

American Association of Mental Deficiency Adaptive Behaviour Scale (Nihira, Lambert, & Leland, 1993)

The American Association of Mental Deficiency Adaptive Behaviour Scale (second edition; AAMD ABS: 2) is a carer rated scale of adaptive behaviour, specifically designed to assess the likelihood of dementia in someone with DS and, by extension, people with ID. It is split into adaptive (ten subscales) and maladaptive behaviour domains (eight subscales).

Reliability. The test-retest values, internal consistency, and inter-rater reliability are all high or extremely high. In addition, the rank order correlations for both the younger group (< 30 years) and older group (≥ 30 years) are both similar at follow-up, suggesting the AAMD ABS: 2 provides a reliable measure of adaptive behaviour at the time (Zigman, Schupf, Urv, & Silverman, 2009).

Validity. Overall, markedly different profiles were seen with regard to age and diagnosis in people with DS, with profiles of the younger group (< 30 years) without dementia, older individuals (≥ 30) without dementia, and the older group (≥ 30) with dementia showing different profiles. This indicates that the assessment shows differences between groups. The same study also indicated that the profiles of the older and younger people who were not dementing significantly correlated with each other ($r = 0.82$), indicating a profile of adaptive abilities common to those who do not have dementia (Prasher, Krishnan, Clarke, & Corbett, 1994).

However, the subscale of vocational activity holds well through age, therefore confounding the results of the overall scale. This could lead to inaccuracy of the results. In addition, decline in scores occurs with age which could incorrectly be interpreted as being due to dementia. That being said, the overall scores of people with and without dementia showed markedly different profiles, with those with dementia scoring lower than those

without in physical development, language development, numerical ability and concept of time sense, and social skills subscales (Prasher et al., 1994).

The scale was found to be unaffected by gender and whether individuals had DS or non-specific ID and to correlate well with scores on the Dementia Questionnaire for People with Learning Disabilities (DLD; Kirk et al., 2006).

Sensitivity and specificity of the measure were both very high (Silverman, Devenny, Krinsky-McHale, Ryan, & Zigman, 2006).

Assessment of Motor and Process Skills (Fisher & Jones, 2014)

The Assessment of Motor and Process Skills (AMPS) is based on an occupational therapist's observation of the individual engaging in daily tasks in order to obtain an overview of their performance of motor and process skills, scoring both. These are then entered into a computer scoring system that is calibrated to the individual therapist. The latest version of the AMPS (eighth edition) was published in 2014. The tool has been standardised on a sample of 148,158 persons, including people with and without disabling conditions and medical diagnoses. It is designed for anyone experiencing challenges in activities of daily living ("Assessment of Motor and Process Skills," 2016). It was not specifically designed or standardised for people with ID and dementia.

Reliability. Hitch (2007) provides an overview of the reliability and validity of the AMPS and concludes that this has been established, although this research is not specific to people with ID. No published papers were found in relation to the reliability of the eighth edition of the AMPS (2014) in respect of people with ID, either with or without dementia.

Validity. As above, Hitch (2007) concludes that the validity of the AMPS has been established, but this does not specifically refer to people with ID or ID and dementia. In addition, this overview was conducted in relation to research on the older versions of the AMPS.

Research by Mesa, Heron, Chard, and Rowe (2014) found a low, non-significant correlation between IQ and AMPS (r = 0.226) in 124 people from an ID service (although they included people with IQs in the borderline range). This paper does not specify which version of the AMPS was used, but it appears not to have been the most recent version as the study used pre-existing data.

No published papers were found in relation to the validity of the eighth edition of the AMPS (2014) in respect of people with ID, either with or without dementia.

Dementia Screening Questionnaire for Individuals with Intellectual Disabilities (Deb, Hare, Prior, & Bhaumik, 2007)

The Dementia Screening Questionnaire for Individuals with Intellectual Disabilities (DSQIID) was designed to screen for dementia in people with ID and is split into four sections; the first collecting background information about the person. The second section addresses the optimal level of functioning in relation to speech and living skills, and where the person currently lives. The third requires informant ratings of specific abilities, such as initiating conversation. Finally, the fourth section includes informant responses to a series of simple statements. The measure was found to have no floor effects when evaluated with a group of adults with DS, with and without dementia.

Reliability. The assessment has overall strong internal reliability, test-retest reliability, and inter-rater reliability (Deb et al., 2007).

Validity. Sensitivity and specificity were both high when using a cut-off score of 20, based on a comparison of adults with (N = 29) and without (N = 49) dementia (Deb et al., 2007).

Adaptive Behaviour Dementia Questionnaire (Prasher, Farooq, & Holder, 2004)

The Adaptive Behaviour Dementia Questionnaire (ABDQ) is an assessment of adaptive behaviour designed to screen for dementia in adults with DS. Unlike other scales, some questions are weighted more heavily than others.

Reliability. The assessment shows very high inter-rater reliability and good split half validity (Prasher et al., 2004).

Validity. In a sample including people with AD, using a weighted scoring method, scores greater than 78 indicates the presence of dementia. Both sensitivity (89%) and specificity (94%), and positive predictive validity (89%) and negative predictive validity (94%) are high. The overall percentage of correct identification (both with and without AD present) was 92% (Prasher et al., 2004).

Gedye Dementia Scale for Down Syndrome (Gedye, 1995)

The Gedye Dementia Scale for Down Syndrome (G-DSDS) was designed to assess dementia in people with DS. It is a 60 item informant based questionnaire designed to track changes over time (being completed every 6-12 months). When a decrease is seen in three cognitive areas, the person is identified as being likely to have dementia (Jozvai, Kartakis, & Gedye, 2009).

Reliability. Inter-rater reliability was shown to be high (0.91; Gedye, 1995).

Validity. The assessment appears to track change over time. Participants who met the criteria for late stage dementia had previously met the criteria for early and middle stage dementia. Those who met the criteria for middle-late stage dementia had scores lower than those in the early stages. When comparing the G-DSDS against a clinician's diagnosis of dementia it performed well, producing both high sensitivity (0.85) and specificity (0.89; Gedye, 1995). In matched sample tests, the sensitivity was adequate (0.65), specificity was excellent (1.0), positive predictive power was excellent (1.0), and negative predictive power was quite good (0.76; Shultz et al., 2004). It has also been reported that the G-DSDS

correlates well with the Dementia Questionnaire for People with Learning Disabilities (DLD; Deb & Braganza, 1999).

It has been suggested that the G-DSDS may be more useful for assessing people with a profound ID, as at baseline assessment the scale yielded a sensitivity of 0.58 and a specificity of 0.96. However, at a two year follow-up, sensitivity had increased to 0.75 and specificity had stayed stable at 0.96 (Huxley, Prasher, & Haque, 2000). This disparity is argued as mainly due to higher functioning individuals within the group.

Multidimensional Observation Scale for Elderly Subjects (Helmes, Csapo, & Short, 1985)

The Multidimensional Observation Scale for Elderly Subjects (MOSES) is a carer rated scale originally designed to assess the physical needs and intellectual functioning of older adults. Since its development, it has been used with people with ID. It was developed through empirical factor analysis of earlier assessments of functioning (Helmes et al., 1985) and later validated (Helmes, Csapo, & Short, 1987). The scale consists of five, evenly weighted, subscales.

Reliability. The reliability statistics reported below do not relate to people with ID unless specified. The inter-rater reliability scores of the subscales, rated across multiple settings, show mixed results. The lowest value is for depression (0.58); the two highest being disorientation (0.84) and self-care (0.97; Helmes et al., 1987). The internal consistency of the subscales of withdrawal (0.78), irritability (0.79), depression (0.80), and self-care (0.82) are all similar, whilst disorientation is superior (0.87). This shows good grouping of the subscales (Helmes et al., 1987).

Two studies in relation to people with ID, including participants with AD, found that the inter-rater reliability of the scale was 0.85 on average across three raters (Dalton, Fedor,

Patti, Tsiouris, & Mehta, 2002) and the overall scale had good internal consistency (Sturmey, Tsiouris, & Patti, 2003).

Validity. The authors demonstrated the validity of the assessment by examining the relationship between scores and the present condition of the person. Helmes et al. (1987) found that those who were transferred home from hospital performed markedly better on the self-care and disoriented behaviour subscales than those who were dying; those who were in the process of being transferred from hospital to a home were more depressed and anxious, and those who had been transferred were less irritable than those who were dying. Less withdrawn behaviour was seen by those who were being transferred compared to those dying or in hospital.

National Task Group - Early Detection Screen for Dementia (Esralew et al., 2013)

The National Task Group - Early Detection Screen for Dementia (NTG-EDSD) questionnaire is an adaption of the Dementia Screening Questionnaire for Individuals with Intellectual Disabilities (DSQIID) and is designed to act as a screen for signs and behaviours which may indicate a presence of dementia (Esralew et al., 2013). Change on the measure indicates the need for further assessment of dementia. The questionnaire comprises sections relating to health, mental health, life stressors, and demographic information.

Reliability and validity. The questionnaire is based on the DSQIID which is a highly reliable tool for assessing the presence of dementia in people with ID. The properties of the adapted NTG-EDSD are not known.

Assessment for Adults with Developmental Disabilities (Kalsy, McQuillan, Oliver, & Hall, 2002)

The Assessment for Adults with Developmental Disabilities (AADS) is an informant questionnaire designed to detect changes due to dementia in people with ID. The assessment contains two subscales that describe behavioural excesses (e.g., wandering, aggression) and

deficits (e.g., inactivity, withdrawal) through the development of dementia. Questions are scored in terms of frequency of behaviour, allowing a wide range of possible scores (Kalsy et al., 2005).

Reliability. The intra-class correlations for excesses and deficits and the number of excesses were reported as high. The intra-class correlations for the management of excesses and deficits and the effect of excesses and deficits and the intra-class correlation coefficients were moderate to high (Kalsy, Oliver, McQuillan, & Hall, in review, as cited in Kalsy et al., 2005).

Validity.

Concurrent validity. Those with cognitive deterioration showed a significant increase in behavioural excesses (Adams & Oliver, 2010). Scores on the AADS correlate highly with those on the Dementia Questionnaire for People with Learning Disabilities (DLD; Oliver et al., 2011).

<Insert Table 3>

Conclusion

Screening for, and the assessment of, dementia in individuals with ID remains challenging. The review illustrates that the performance of assessments may vary depending on the characteristics of the individual, such as age, severity of ID and premorbid functioning. The clinician must also determine if measured decline in cognitive and adaptive functioning is over and above that due to the aging process, rather than dementia. As there is relatively little research in relation to the normal ageing process in people with ID, this represents a further methodological and clinical challenge. The review illustrates, however, that a wide range of assessments of cognition and behaviour exist, many of which have been developed specifically in relation to individuals with ID (usually individuals with DS). Of those that were specifically standardised for the purpose of assessment in relation to

dementia, few had comprehensive information about both reliability and validity. The CS-DS and PCFT had the best range of available information about, and strongest psychometric properties in respect of measures of cognitive function. The AAMD ABS:2 and DSQIID were the best measures, based on these same criteria, in respect of assessments of adaptive functioning.

The review highlights the need for further research in this area. While a number of measures were designed specifically for people with DS, reflecting the higher risk of AD that this group face (Lott & Dierssen, 2010; Strydom et al., 2009), the increasing life span of people with ID in general and the associated risk of developing AD (McCarron et al., 2010), indicates the need for measures that can reliably measure dementia in people with ID who do not have DS. There is also a need for further research into the psychometric properties of existing measures, with many only having limited published information about their performance when used with people with ID.

The measure that is ultimately chosen is, however, likely to vary depending on a number of factors. Prasher (2018) provides a list of helpful considerations for the clinicians when choosing a suitable measure, including practical issues, such as the time an assessment takes, test user requirements and cost; the purpose of conducting the assessment e.g. for screening or to inform diagnosis; and performance issues, such as the applicability of assessments designed for the general population to people with ID. It is recommended that clinicians consider the performance and psychometric properties of the measures they choose in this wider context. It is hoped that the current review will help clinicians with making these decisions.

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Table 1. Search strategy, one from each row must be present in the result.

		AND	AND
OR	Dementia	Down syndrome	Screening
OR	Alzheimer's	Intellectual disability	Diagnosis
OR		Learning disability	Screen
OR			Screening tool
OR			Assessment
OR			Measure
OR			Test
OR			Validity
OR			Reliability

Table 2. A summary of cognitive measures

Cognitive Measures							
Scale	**Assessment Method**	**Use with people with Intellectual Disability (ID)[a]**	**Reliability**		**Validity**		**Summary**
			Score[b]	**Available information[c]**	**Score[b]**	**Available information[c]**	
Cambridge Examination for Mental Disorders of the Elderly, modified for use assessing people with Down Syndrome (CAMDEX-DS)	Direct assessment	2	3	1	3	3	While there is limited information on reliability, the CAMDEX-DS appears to be a valid tool for aiding the diagnosis of dementia, which has been standardised for use with people with ID.
Cambridge Cognitive Examination, modified for use in a group with	Direct assessment	2	0	0	3	3	While no reliability information specific to the CAMCOG-DS could be found, research demonstrates the CAMCOG-DS is a valid method of tracking change associated with Alzheimer's disease (AD) within, and

Down syndrome (CAMCOG-DS)							between, groups. It has been standardised for use with people with ID. Hon and colleagues (1999) suggest that the assessment is not useful for people in the late stages of dementia or with severe ID.
Dementia Questionnaire for People with Learning Disabilities (DLD)	Informant	2	1	1	2	3	The DLD has poor inter-rater reliability, particularly on behaviour and disturbance items. Sensitivity and specificity values for people with ID and dementia are variable, but good for people with Down syndrome (DS) and dementia. Research suggests it should not be used with people with severe ID, although inter-rater agreement has been found to be better for individuals with ID who are less able.
Down Syndrome Mental Status Examination (DSMSE)	Direct assessment	2	0	0	2	2	No information was found about the reliability of the measure. There is some evidence that it can discriminate between those with and without dementia in individuals with a moderate ID (although age may influence scores), but it appears unsuitable for use with individuals with a severe ID.
Cognitive Scale for Down	Informant	2	3	3	3	2	The CS-DS is a relatively new scale, but initial research has suggested that it

Syndrome (CS-DS)							has good psychometric properties. Further independent research is needed on the measure.
Severe Impairment Battery (SIB)	Direct assessment	1	3	1	2	2	The SIB is used with some frequency with people with ID. While there has been limited evaluation in relation to people with ID, the available research has suggested that it has good test-retest and concurrent validity.
Rivermead Behavioural Memory Test – 3rd edition (RBMT-3)	Direct assessment	1	3	1	3	1	Overall, earlier versions of the RBMT have shown good psychometric properties. There has been limited research on the most recent version and in relation to people with ID. Previous research has suggested that it may have some utility when used with people with DS, but may demonstrate floor effects in individuals with more severe ID or those who already have dementia.
Dementia Rating Scale (DRS)	Individual assessment	1	N/A	N/A	2	1	There is limited research in relation to people with ID. Further research is needed to clarify the psychometric properties of the assessment when used with people with ID and dementia.

Test for Severe Impairment (TSI)	Direct assessment	1	2	2	2	2	The test has a very short administration time (approximately ten minutes). There is some evidence of reliability and validity in relation to people with ID, although the sample size was small and the research was conducted a number of years ago.
Mini-Mental State Examination (MMSE)	Direct assessment	1	N/A	N/A	1	1	There is very little information on the use of the MMSE with people with ID. Further research is needed to establish its psychometric properties in relation to people with ID and dementia.
Neurotrax Computerized Moderate to Severe Impairment Battery	Direct assessment	2	3	1	1	1	Very limited information is provided regarding the reliability of the measure. Limited validity information was provided as well, but authors state it can be used to track change through time.
Prudhoe Cognitive Function Test (PCFT)	Direct assessment	2	3	3	3	2	Further validity information would be desirable. What is available indicates this measure shows promise due to its high concurrent validity with other standardised measures.

[a] Use with people with ID: 2 = standardised for use with people with ID; 1 = has been used with people with ID; 0 = not standardised for use or used with people with ID.

[b] Reliability/Validity - Score: 3 = good; 2 = adequate; 1 = low; 0 = unacceptable /no information provided; N/A = measure may have good reliability/validity, but this does not relate specifically to people with ID.

[c] Reliability/Validity - Available Information: 3 = information on range of key types available; 2 = restricted range of information available/focus on less relevant types of information; 1 = limited information provided; 0 = no information provided; N/A = measure may have information available, but this does not relate to people with ID.

Note: Ratings are based on information from sourced published papers. In some cases, information may be available but was not accessible to the reviewers.

Table 3. A summary of behaviour measures

Behaviour Measures							
Scale	**Assessment Method**	**Use with people with Intellectual Disability (ID)[a]**	**Reliability**		**Validity**		**Summary**
			Score[b]	**Available information[c]**	**Score[b]**	**Available information[c]**	
Vineland Adaptive Behaviour Scales – 3rd edition (VABS-III)	Informant interview	1	N/A	N/A	N/A	N/A	The VABS-II was a commonly used assessment within ID services. While not designed specifically to track behavioural decline in people with ID, it has been used for this purpose. The VABS-III has recently been published and to date no research is available in relation to its use with people with ID and dementia.
Adaptive Behaviour Assessment System – 3rd edition (ABAS-3)	Self-report and informant versions	1	N/A	N/A	N/A	N/A	The ABAS-3 has limited psychometric information relevant to people with ID. While reliability appears adequate to good, based on general population samples, there is limited information about the validity of the assessment. This raises questions about how well it would

							perform as part of an assessment for dementia.
American Association of Mental Deficiency Adapted Behaviour Scale – 2nd edition (AAMD ABS: 2)	Informant	2	3	3	3	3	The AAMD ABS: 2 has good reliability and ability to discriminate between groups by age and diagnosis in terms of those with and without dementia, with the exception of the vocational activity subscale which holds through age. It may be advisable to exclude this scale. There does not appear to be any longitudinal studies of the AAMD ABS: 2 with people with dementia.
Assessment of Motor and Process Skills (AMPS)	Observational	1	N/A	N/A	N/A	N/A	There is limited research in relation to the validity and reliability of the AMPS as used with people with ID. No published research about the psychometric properties of the most recent version of the AMPS could be found in relation to people with ID, either with or without dementia.
Dementia Screening Questionnaire for Individuals with Intellectual	Informant	2	3	3	3	2	The DSQIID shows good psychometric properties in relation to the assessment of dementia in people with ID.

Disabilities (DSQIID)							
Adaptive Behaviour Dementia Questionnaire (ABDQ)	Direct assessment	2	3	2	3	2	There is only one paper analysing the reliability and validity of this tool (the author's original paper), however this paper does suggest that it is a valid and reliable tool which can be used to screen for dementia in people with Down syndrome (DS).
Gedye Dementia Scale for Down Syndrome (G-DSDS)	Informant	2	3	1	2	3	There is limited independent research into the reliability of the measure, however the authors' reported inter-rater reliability is high. The measure also appears to have good validity, but may be more useful for assessing change in individuals with more severe intellectual impairments.
Multidimensional Observation Scale for Elderly Subjects (MOSES)	Informant	1	3	2	N/A	N/A	While not originally designed for individuals with ID, it may have some utility in informing the support needs of the person. There is some indication that it is reliable when used in relation to people with ID, but research is needed into its validity with this population.

National Task Group – Early Detection Screen for Dementia (NTG-EDSD)	Informant	2	N/A	N/A	N/A	N/A	The NTG-EDSD is based on an adaptation of a measure with good psychometric properties, but its own properties have not been independently assessed.
Assessment for Adults with Developmental Disabilities (AADS)	Informant	2	2	2	2	1	There is only limited information available about the reliability and validity of the AADS, but this suggests that intra-class correlations are generally moderate to high and that there is an association between cognitive deterioration and increases in behavioural excesses.

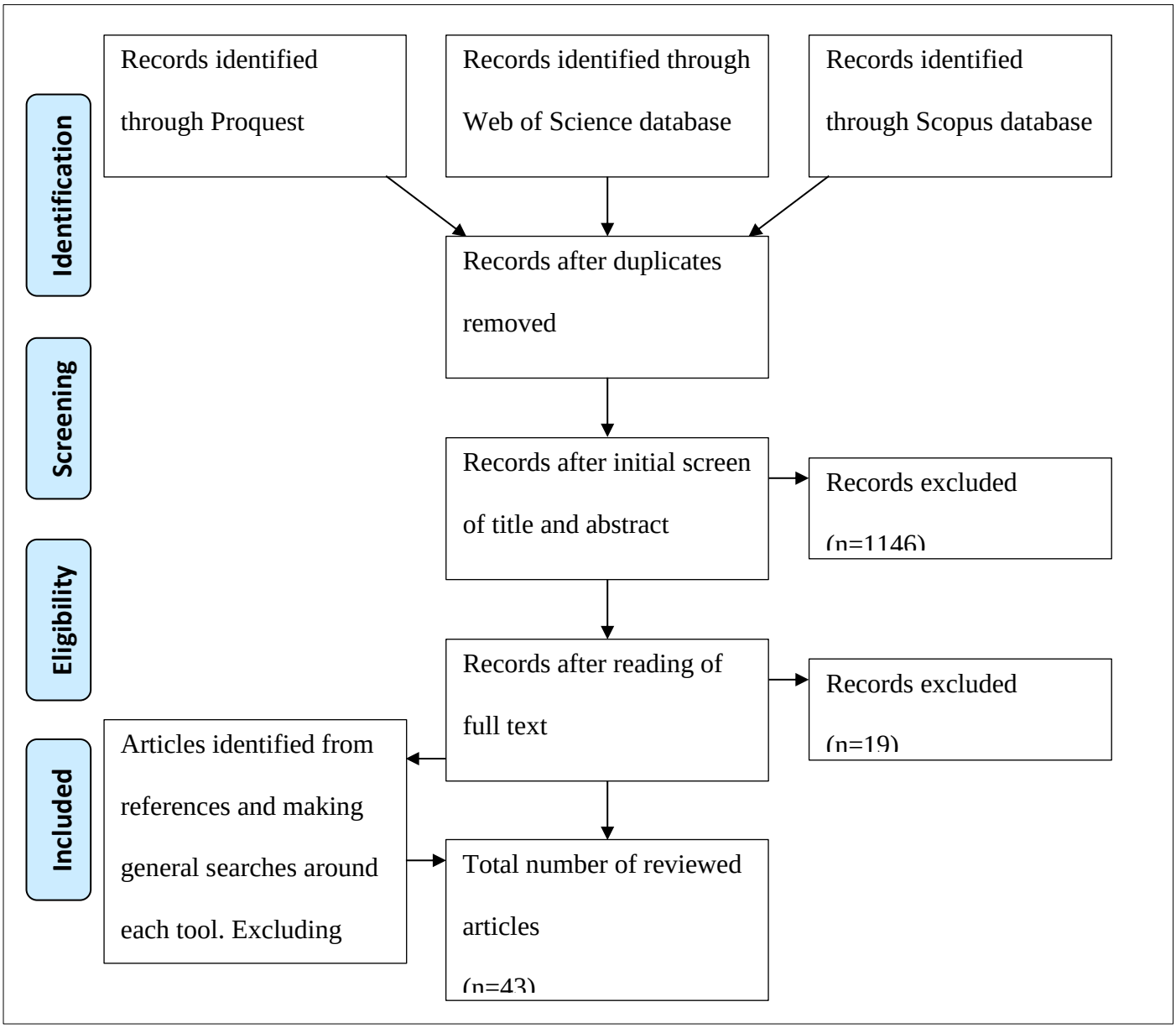
[a] Use with people with ID: 2 = standardised for use with people with ID; 1 = has been used with people with ID; 0 = not standardised for use or used with people with ID.

[b] Reliability/Validity - Score: 3 = good; 2 = adequate; 1 = low; 0 = unacceptable /no information provided; N/A = measure may have good reliability/validity, but this does not relate specifically to people with ID.

[c] Reliability/Validity - Available Information: 3 = information on range of key types available; 2 = restricted range of information available/focus on less relevant types of information; 1 = limited information provided; 0 = no information provided; N/A = measure may have information available, but this does not relate to people with ID.

Note: Ratings are based on information from sourced published papers. In some cases, information may be available but was not accessible to the reviewers.

Figure 1. PRISMA diagram of search procedure



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