Guidance on Neuropsychological Testing with Individuals who have Intellectual Disabilities

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Editions 1 and 2: Heather Liddiard & Carol Hagland;
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Section 1: Introduction

Objectives

This guidance aims to provide clinical and other qualified psychologists with information to support them in carrying out neuropsychological assessments with adults with intellectual disabilities.

This guidance does not cover assessment to determine if an individual has intellectual disabilities. The assessment and diagnosis of intellectual disabilities in adulthood is covered in detail by other British Psychological Society guidance (see BPS, 2015b).

Selecting, administering and interpreting neuropsychological tests with adults with intellectual disabilities presents a number of challenges. For example, few neuropsychological tests have been developed for, or provide normative data for adults with intellectual disabilities.

This guidance aims to:
- Provide a context for thinking about and understanding neuropsychological assessment in this population;
- Consider the situations where neuropsychological testing may be helpful;
- Highlight important considerations in the selection, adaptation and interpretation of tests;
- Highlight important considerations in the administration of tests;
- Provide information on tests that may be useful with this population.

The guidance is devised for use by qualified psychologists only and does not require that they undertake additional training. Assistant psychologists and trainee clinical psychologists may undertake some of the testing described here under the supervision of a qualified psychologist. Where this is done the qualified psychologist must check all parts of the work, particularly scoring and interpreting the results.

Recommendations

Clinical and other qualified psychologists should:
- Review their skills in the selection, administration and interpretation of tests;
- Where appropriate, seek opportunities to develop or update these skills;
- Seek supervision from clinical psychologists or neuropsychologists with extensive experience in this area.

Assessment of acquired neurological insult/injury or complex neurological presentation in individuals with pre-existing intellectual disabilities should be undertaken in collaboration with or under the supervision of a neuropsychologist.
Rationale

Neuropsychological assessment provides a means of identifying an individual’s cognitive strengths and weaknesses. This information can be used to adapt their environment to maximise their strengths and provide support that compensates for their weaknesses (Lamb, 2010). Assessment results provide an evidence base to challenge the, often incorrect, assumptions about an individual’s abilities and understanding, and give a basis for building a more helpful understanding of the individual and the support they need.

Neuropsychological testing may be indicated in a number of situations including:

- As part of a diagnostic assessment;
- Assessment for possible organic changes;
- As part of assessment of the effects of epilepsy on cognitive processes;
- Identifying support needs;
- Contributing to determining mental capacity and informing ability to engage in legal proceedings (e.g. fitness to plead);
- Contributing to a functional assessment of challenging behaviour/offending behaviour;
- Contributing to an assessment of Alzheimer’s disease and other dementias (see BPS, 2015a);
- Contributing to an assessment around parenting (see BPS, 2011a);
- Contributing to the assessment and management of risky behaviours.

Neuropsychological testing can help provide a profile of an individual’s cognitive abilities to answer questions such as:

- Are the individual’s abilities being over/underestimated?
- Has the individual experienced a decline in their ability levels over time?
- Are the presenting problems due to a specific neuropsychological deficit (rather than an emotional, environmental or health issue)?
- How does the individual learn and remember best?

In the past neuropsychological assessment was used to help identify where in the brain damage might have occurred. However, neuro-radiological techniques have advanced to such an extent that structural changes within the brain can often be identified using cerebral CT and MRI scanning. While there is no longer a need to use the results from neuropsychological assessments for this purpose, testing may identify subtle deficits where no structural abnormalities are detected.

Whatever the reason for assessment, the results of testing should contribute to formulation and the development of appropriate interventions/remediation.

Recommendations

Neuropsychological testing should be undertaken to answer specific questions about an individual’s cognitive functioning.

Neuropsychological testing must always be part of a wider assessment that contributes to an holistic formulation.
Clinical population
This guidance is intended for use with adults with intellectual disabilities including those with severe and significant intellectual disabilities.

National Institute for Health and Care Excellence (NICE) guidance
There are no NICE guidelines specifically for neuropsychological assessment. However, the NICE guidance on dementia (CG42) recommends that individuals with suspected dementia should have cognitive assessments that look at attention and concentration, orientation, short and long-term memory, praxis, language and executive function and that formal neuropsychological testing should form part of the assessment in cases of mild or questionable dementia. NICE guidance on Stroke (CG68) recommends that all individuals have a cognitive screen as part of their care pathway. Other NICE guidance that may be relevant, depending on the clinical question, include: Attention Deficit Hyperactivity Disorder (CG72); Epilepsy (CG137); Multiple Sclerosis (CG8); and Parkinson’s disease (CG35). To find NICE guidance go to www.nice.org.uk and use the ‘find guidance’ page.

Recommendation
Clinical psychologists should check whether there is NICE guidance that is relevant to the issues being assessed and, where guidance exists, should follow NICE recommendations.
Section 2: Context

This section includes information that may be helpful in thinking about neuropsychological testing with individuals with intellectual disabilities. It considers the definition and causes of intellectual disabilities. It outlines the nature of cognitive functions and the cognitive profiles/phenotypes of some conditions associated with intellectual disabilities. It highlights areas where background information should be sought and also gives guidance on assessment of individuals from different cultural backgrounds.

Definition of intellectual disabilities

A number of classification systems and papers describe what constitutes an intellectual disability. These include the *Diagnostic and Statistical Manual of Mental Disorders—DSM-5* (American Psychiatric Association, 2013), the *International Classification of Diseases—ICD-10* (World Health Organisation, 1992), *Valuing People* (Department of Health, 2001), and *Guidance on the Assessment and Diagnosis of Intellectual Disabilities in Adulthood* (British Psychological Society 2015b) The core themes throughout these references are that an individual with an intellectual disability has:

1. A significant impairment of intellectual functioning;
2. A significant impairment of adaptive social functioning;
3. Age of onset before adulthood.

**Recommendation**

Any discussion of intellectual disability that forms part of the interpretation of a neuropsychological assessment should comply with the BPS guidance (2015b).

Causes of intellectual disabilities

There are multiple causes of intellectual disabilities. Some of the most common identifiable causes are:

- Genetic/chromosomal abnormalities;
- Deprivation of oxygen during gestation or birth;
- Brain malformation during gestation;
- Early severe psychosocial deprivation/severe neglect;
- Exposure to toxins during gestation, including maternal alcohol and other drug use (mothertobaby.org fact sheets).

Advances in medical research and investigation techniques such as cerebral MRI and genetic testing mean that more causes of intellectual disabilities are being identified: the proportion of individuals where no cause can be found is consequently falling.

Whatever the initial cause of the intellectual disability, environmental factors play a role in on-going development (Weis, 2014). Brain development is characterised by the formation and pruning of synapses. This process is influenced by factors such as nutrition, the quality of caretaking, environmental stimulation, and teaching. Development may be distorted by exposure to toxins (e.g. lead), illness (e.g. meningitis) or injury (Weis, 2014).
Consequently every adult with intellectual disabilities will have a unique cognitive profile that is the product of these processes.

**Understanding cognition**

Knowledge regarding the specific nature of brain structures and functions has significantly increased over the last century (Johnstone & Stonnington, 2009). Knowledge gained from research and case studies has shown that the brain is responsible for numerous functions including memory, attention, and reasoning, regulating emotions and behaviours and receptive and expressive communication. The ability of the brain to carry out these functions can be compromised by both environmental and physiological factors, such as exposure to toxins, trauma, and by the aging process across the lifespan (Johnstone & Stonnington, 2009).

There is a vast body of theory and research that seeks to explicate cognitive functioning in the general population. There is also a plethora of research into the neuropsychological assessment of individuals whose functioning has been compromised by brain trauma, vascular events or dementia. The research has not only explored the types of cognitive deficits observed in these conditions but also the tests that can help to identify the cognitive impairments in these conditions. However, research into these issues in individuals with intellectual disabilities is much more limited and patchy.

**Understanding and measuring general intellectual ability**

There is a vast literature on the concept of general ability or intelligence. Cognitive ability was originally attributed to a single function labelled ‘intelligence’ but subsequent work identified a range of underpinning specific cognitive abilities (Lezak, 1995). However, individuals who score well on a test of one cognitive ability tend to score well on other cognitive tests. General cognitive ability is now estimated through subtests sampling a range of abilities which are used to calculate a composite ‘IQ’ score. The British Psychological Society (2015b, p.16) considers the characteristics that are important in tests of general ability. Lezak (1995) highlights that, while such composite scores are often good indicators of academic performance, they may obscure specific and clinically significant deficits.

The subtests chosen and the way in which they are combined to create IQ scores are underpinned by the model of ‘intelligence’ used by the test maker. For example, the WAIS-IV is based on a four-factor model. However, it is important to be aware that there is no single, agreed understanding of intelligence/general ability. For example, Lichtenberger and Kaufman (2009) present alternative models that can be used to interpret WAIS-IV test results.

**General intellectual ability in people with intellectual disabilities**

By definition individuals with intellectual disabilities have impaired general cognitive abilities. Simplistically, it may be considered that there are two developmental pathways for individuals with intellectual disabilities; global delay, where development is typical but slow and with a lower endpoint and atypical development. Where development is atypical,
this leads to patterns of cognitive strengths and weaknesses. Particular syndromes often have characteristic cognitive patterns. These patterns are part of a behavioural phenotype.

A behavioural phenotype may be defined as:
‘The heightened probability or likelihood that people with a given syndrome will exhibit certain behavioural or developmental sequelae relative to those without the syndrome.’ (Dykens, 1995)

Behavioural phenotypes have been identified for chromosomal disorders such as Down’s syndrome (Chapman & Hesketh, 2000), single gene mutations such as Angelman syndrome (Horsler & Oliver, 2006) and environmental causes such as foetal alcohol syndrome (Kodituwakku, 2007). Some cognitive profiles are presented in more detail later in this section.

Understanding and measuring memory

‘Memory involves the complex of systems by means of which an organism registers, stores, retains, and retrieves some previous exposure to an event or experience.’ (Lezak, 1995).

These complex systems are conceived and configured in different ways by different models of memory. Memory concepts relate to the modality through which the information is absorbed, the length of time it is retained for, the way by which it is retrieved and whether the information to be recalled is in the past or the future.

Not all memory processes are assessed by all memory tests. It is important to generate hypotheses about what areas of memory functioning may be relevant to the presenting problem to help in the selection of tests. Lezak (1995) highlights that difficulties subjectively reported as being a ‘poor memory’ may in fact arise from difficulties with attention. An individual is unlikely to be able to remember material if they have not attended to it. Measures of attention may be needed to clarify this issue.

Some of the memory processes assessed by memory tests are described below:

- **Working memory** is the process by which information is held in mind while the individual uses it to problem solve; for example, holding a question in mind while generating or calculating the answer. The idea of multi-modal working memory was proposed in 1974 by Baddeley and Hitch. This working memory model explains many practical observations, such as why it is easier to do two different tasks (one verbal and one visual) than two similar tasks (e.g. two visual).

- **Immediate memory** is the ability to retrieve information after a short time period (a few seconds).

- **Delayed memory** refers to the ability to retrieve information after a longer time period (20 to 30 minutes).

- **Verbal/auditory memory** refer to the ability to remember information that is heard (words and other sounds) and **visual memory** to that presented visually.

- **Long-term memory** is memory for information that has been well processed and integrated into general knowledge store. This may be divided into declarative/explicit (e.g. knowing the capital of France) and non-declarative/implicit (e.g. skills such as how to ride a bike).

- **Episodic memory** is a form of memory in which information is stored with ‘mental tags’ about where, when and how the information was gained.
Retrospective memory relates to storing and retrieving information about things that are in the past (e.g. recalling what happened last Friday).

Prospective memory relates to recalling something at a future time (e.g. remembering to attend a dental appointment next Friday). Prospective memory is particularly important in the organisation of everyday life.

Autobiographical memory refers to the individual’s memory about themselves (e.g. where they went to school and what subjects they did well at).

Information can be retrieved from memory in a number of ways:

- Recall involves bringing the information to mind without any additional cue or prompt.
- Cued recall is when the material is retrieved following some form of prompt (e.g. giving the initials of a name to be recalled).
- Recognition involves deciding on encountering material whether it has been seen/heard before.

Memory in adults with intellectual disabilities

It is recognised that individuals with intellectual disabilities may have difficulties with all forms of memory. Individuals with different syndromes may have very different patterns of strengths and weaknesses in memory skills (Edgin, Pennington & Mervis, 2010). Certain patterns of memory problems have been identified in particular disorders. This information is presented later.

The memory skills of individuals with intellectual disability are of critical importance where they are the suspected perpetrator, victim or witness of crimes (Beail, 2002).

Understanding and measuring attention

The term ‘attention’ covers a number of cognitive processes that relate to actively processing information from the environment, focusing on certain aspects and filtering out others. Attentional functions mediate other cognitive processes. Levitt and Johnstone (2009) highlight the discrepancies within the literature on attention with discrepant terms referring to similar if not identical cognitive processes. They suggest a taxonomy of basic attentional abilities. This comprises:

- Arousal: level of alertness, ability to respond to the environment.
  - Tonic arousal: day-to-day alertness, unrelated to immediate demands of task.
  - Phasic arousal: ability to respond to changes in the environment or task requirements.
- Focused attention: ability to focus attention on a specific stimulus while ignoring other stimuli.
- Divided attention: ability to pay attention to more than one stimulus at a time, to switch attention between tasks or process information while simultaneously holding other information in consciousness.
- Sustained attention (vigilance): ability to maintain attention over extended time frames.

Attention may also be considered in relation to the primary sense involved, that is, visual or auditory processing.
Lezak (1995) highlights the difficulty of assessing and separating different aspects of attention, concentration and tracking. She comments that ‘clarifying the nature of an attentional problem depends on observation of the patient’s general behaviour as well as performance on tests… for only by comparing these various observations can the examiner begin to distinguish global deficits of attention from the more discrete, task specific problems of concentration and tracking.’

Attentional deficits may involve one receptive or expressive modality more than others.

**Development of attention in typically developing individuals**

Ability to sustain attention increases with age from very limited at age 1 to 2 years to the ability to concentrate for long periods as an adult. The development of attentional functioning may be described in terms of levels achieved (Cooper, Moodley & Raynell, 1978):

Year 1: Extremely distractible, fleeting attention, easily distracted.

Year 2: Can concentrate on task of own choosing, intolerant of intervention by others, attention single channelled, ignoring other stimuli when concentrating.

Year 3: Attention still single channelled, cannot attend to auditory and visual stimuli from different sources.

Year 4: Can spontaneously alternate attention between auditory and visual stimuli.

Year 5: Attention two channelled i.e. can integrate visual and auditory stimuli, short attention span.

Year 6: Auditory, visual and tactile channels are well integrated, attention well established and sustained.

**Attention in adults with intellectual disabilities**

It is recognised that individuals with intellectual disabilities may have shorter attention spans and be more distractible than their peers without intellectual disabilities. Social aspects of attention have been studied in individuals with autism, for example, failures of ‘shared attention’. There are also some studies suggesting specific deficits in attention in individuals with specific disorders. This research is presented later.

**Understanding and measuring executive functioning**

Executive functioning is a generally accepted term for complex cognitive processes that serve ongoing, goal directed behaviour. However, there is no single agreed model of executive functioning. Callahan (2009) reflects that ‘for models purporting to describe the same construct, there is a striking lack of concordance’. There are also significant overlaps between the features within any given model (Callahan, 2009; Jurado & Rosselli, 2007).

Models of executive functioning often include the following elements:

- Goal setting and planning;
- Organising behaviour over time;
- Flexibility;
- Self-regulation.

Some models also include attention and working memory as these are pre-requisites for higher executive functions.
Lezak et al. (2004) group executive functions into four components: (1) volition; (2) planning; (3) purposeful action; and (4) effective performance. They note that each of the four components necessitates a distinctive set of activity-related behaviours for appropriate, socially responsible, and effective adult conduct.

**Volition** is the capacity for intentional behaviour and comprises; determining one’s needs/wants, identifying a goal and the motivation to initiate achieving the goal.

**Planning** comprises identification and organisation of the elements (e.g. skills, materials and people) and steps needed to achieve a goal.

**Purposeful action** comprises translation of intention and planning into productive activity.

**Effective performance** comprises monitoring, self-correction and self-regulation during an activity.

Research literature shows that executive functioning should be viewed as a collection of correlated, yet separable variables and that these variables are differentially correlated to general intellectual ability (Miyake et al., 2000). It is important to recognise the inconsistent relationship between IQ and executive functioning (Arffa, 2007) that is, executive functioning cannot be reliably predicted from an individual’s IQ score. Consequently the full picture of an individual’s capacity, skill and level of function can only be derived by assessment that includes measures of both general intellectual ability and executive functions.

Among typically developing persons, the maturation of executive function processes is reflected in the ability to be more future oriented, less stimulus bound, and less concrete. Executive functions develop throughout childhood and adolescence and peak in young adulthood (Russo et al., 2007). Research reviewed by Jurado and Rosselli (2007) indicates that executive development does not appear to occur homogeneously. Different executive functions have different developmental trajectories. The first to emerge is the ability to inhibit over-learned behaviour (by age 1 year). The ability to inhibit task-irrelevant behaviour shows greatest development between ages 6 and 10 years. Planning and set-shifting develop by age 3 years with significant improvements after age 7 years. Verbal fluency is the last skill to emerge with significant developments at age 8 years and again at 12 years (children generally perform better at category rather than letter fluency tasks).

**Executive functioning in adults with intellectual disabilities**

The literature in this area is limited. However, there are some studies suggesting specific deficits in executive functioning in individuals with Down’s syndrome, Fragile X, Turner’s syndrome and Williams syndrome and disorders on the autism spectrum. This research is presented later. Willner et al. (2010) suggest the structure of executive function seen in people with intellectual disabilities closely resembles the three-factor model of executive functioning (working memory and monitoring, shifting and inhibition of prepotent responses) proposed by Miyake et al. (2000). As in the general population, the scores of individuals with intellectual disability on tests of executive functioning were only weakly related to IQ scores (Willner et al., 2010).
Deficits in executive functioning in people with intellectual disabilities have been linked to challenging and offending behaviour. For individuals on the autism spectrum the more pronounced the features of the executive dysfunction the greater the intensity and frequency of the challenging behaviour (Matson & Rivet, 2008). An analysis of offending patterns and offending behaviours of adults with intellectual disabilities (Nesik, 2008) found significant difficulties with respect to four executive functions: learning from previous experience, logical reasoning, impulse control, and understanding the reactions of others. Saleh et al. (2009) note that clinicians should expect a small minority of sex offenders with intellectual disabilities to show specific executive function deficits. Changes in executive functioning may be the earliest evidence of the onset of dementia in individuals with Down’s syndrome (Ball et al., 2006, 2008).

**Recommendation**

A full picture of an individual’s capacity, skill and level of function can only be derived by assessment that includes measures of both general intellectual ability and executive functions.

**Understanding language**

Language is a complex and specialist area in itself and will not be discussed in detail here. It is important to be aware that language has different components. It is frequently divided into expressive language (the ability to communicate with words/pictures/symbols/signs) and receptive language (the ability to understand words/pictures/symbols/signs). Each of these areas has a number of subcomponents, for example, receptive vocabulary, understanding of grammatical constructs.

**Language in adults with intellectual disabilities**

There is an extensive literature on the development of language in individuals with intellectual disabilities and the language profiles associated with specific syndromes and conditions. This literature is not reviewed here.

The assessment of expressive and receptive language is a specialist area. Consequently tests of language are not reviewed here.

It should be noted that vocabulary tests such as the British Picture Vocabulary Scale are sometimes used by psychologists to give an indication of verbal/global functioning. In this situation the test is not being used specifically to assess language functioning. This use is acceptable provided it is properly explained in the assessment report.

**Recommendation**

Assessments of expressive and receptive language should be completed by a Speech and Language Therapist.
Understanding and measuring perception

Perception is the identification, organisation and interpretation of sensory information in order to represent and understand the environment. Perception involves the stimulation of sensory organs, transmission of that information to the brain by sensory nerves and the brain’s interpretation of those signals. The interpretation of information is also influenced by expectations, past learning and memories. These are complex processes and will not be explored in detail here.

Perception and adults with intellectual disabilities

Individuals with intellectual disabilities are likely to have difficulties with perception. For example, children with intellectual disabilities have deficits in perceptual organisation which correlate with the severity of their intellectual disabilities (Di Blasi, 2007).

This is a specialist area and will not be reviewed here.

Recommendation

Where assessment of perceptual skills is needed this should be carried out in liaison with an occupational therapist and/or a neuropsychologist.

Cognitive profiles of some conditions associated with intellectual disabilities

This section presents some findings in relation to more frequently occurring conditions. However, it is not possible to cover the vast number of syndromes/genetic abnormalities that have been identified.

Hodapp and Dykens (2007) highlight the huge increase in research looking at the behaviour of individuals with specific syndromes that cause intellectual disabilities. They note, however, that this progress is uneven, with more studies performed on Down’s syndrome than on almost all other syndromes combined.

Recommendation

When assessing an individual with a known syndrome, the literature should be checked for the most up-to-date information on cognitive profiles/behavioural phenotypes.

Autism spectrum conditions (ASC)

Autistic spectrum conditions may occur in individuals of widely differing intellectual ability, ranging from severe/profound impairment to those with above average ability. Individuals with ASC also vary in the extent to which they have language disorders.

Where language is significantly impaired, individuals with ASC are likely to show relative strengths on visuospatial/non-verbal measures (Russo et al., 2007). Where language is less impaired there may be strengths in information and vocabulary. Regardless of verbal
ability, processing speed is likely to be impaired (Lichtenberger & Kaufman, 2009). Information of the performance of individuals with autism and Asperger’s syndrome is given in the WAIS-IV manual.

Sigman and Ruskin (1999) found that there was great variation in the change in IQ scores of children with autism over time; the standard deviation increased, with approximately half of the children showing an increase in IQ. This highlights the need for particular caution when making comparisons between testing at different ages for this population.

Individuals with ASC may have difficulties with some aspects of memory. They may have greater difficulty with recall rather than recognition, with a diminished use of sematic or associative relatedness to aid recall (Bowler, Gaigg & Gardner, 2007).

There is a large body of research exploring executive functioning in individuals with ASC. Most of this research has been carried out with children or high functioning adults. Therefore, caution should be exercised in extrapolating the deficits found to adults with ASC and intellectual disabilities.

Pisula (2010) discusses the neuropsychological deficits in people with a diagnosis of ASC. It is posed that executive function deficits can help explain the various difficulties experienced by people with a diagnosis of ASC. In support of this view Ozonoff (1997) found that those with a diagnosis of ASC had difficulty with goal directed behaviour, planning, lack of flexibility in thinking, a tendency to persevere, impulsiveness, and difficulty switching to a new task. Kenworthy et al. (2009) found significant relationships between executive functioning and symptoms of ASC in children. Using the Virtual Errands task, Gnanathusharan et al. (2011) showed that high functioning adolescents with ASC completed fewer tasks, broke more (arbitrary) rules and rigidly followed the task list in order of presentation. They hypothesised that executive problems with planning, inflexibility, inhibition and difficulties with prospective memory may lie behind difficulties with multitasking.

Barnard et al. (2008) compared adults with intellectual disabilities with and without ASC across five domains – planning, inhibition, set-shifting, fluency and working memory. There were no differences between groups in inhibition. While the group with ASC preformed less well on planning, set shifting, fluency and working memory tasks, these differences were not significant. Composite scores for planning and working memory were however effective at discriminating between the groups.

Individuals with ASC are highly likely to have abnormailities of sensory processing. Kern et al. (2006) found that when compared to controls individuals with ASC had abnormal auditory, visual, touch and oral processing, although with the exception of touch, these did improve with age. These included sensory defensiveness and sensation seeking. The presence of sensory processing abnormalities is likely to have a significant impact on the individual’s functioning.

**Recommendation**
Where sensory processing abnormalities are suspected an individual with ASC and intellectual disabilities assessment should be undertaken by/in liaison with an occupational therapist.
**Down’s syndrome (DS)**

All individuals with DS have a degree of intellectual impairment but there are a wide range of abilities. About 10 per cent fall in the borderline-low average range while a minority have profound or severe cognitive impairment. The well-established link between DS and Alzheimer’s disease makes it particularly important to be aware of the characteristics of this population.

A substantial body of research indicates the presence of a specific verbal short-term memory deficit in individuals with DS that persists even when speech and hearing difficulties are accounted for (Mosse & Jarrold, 2010; Rowe et al., 2006). Their performance on visuospatial short-term memory is comparable with peers. It has also been shown that vocabulary development is a relative strength in comparison with more severely delayed aspects of language (Mosse & Jarrold, 2010). Individuals with DS are also significantly slower than matched non DS individuals on a measure of motor speed (Rowe et al., 2006).

Individuals with DS without Alzheimer’s disease perform less well on tests of executive functioning than matched peers (Rowe et al., 2006). It is now also recognised that the early presentation of Alzheimer’s in DS is characterised by prominent personality and behaviour changes, associated with executive dysfunction (Ball et al., 2006, 2008) and that a decline in executive functioning precedes changes in memory functioning. Those who show this decline in executive functioning (sometimes referred to as ‘frontal type dementia’) are more likely to go on to develop Alzheimer’s disease (Ball et al., 2006).

However, Rowe et al. (2006) note that there is a high level of variation between individuals with DS and they recommend comparison to an individual baseline rather than normative data. Research examining the development of cognitive functioning in children with DS has shown a pattern of decline in IQ over time, that is, children with Down’s syndrome fall progressively further behind their typically developing peers (Patterson et al., 2012). Hence caution should be exercised when making comparisons with assessments made in early childhood.

For a more detailed discussion of Alzheimer’s disease/dementia in individuals with DS see BPS (2015a).

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**Recommendation**

Assessment of individuals with DS and suspected dementia should follow the recommendations of the BPS (2015a) guidance.

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**Fragile X syndrome (FXS)**

FXS occurs in both males and females. While most males with FXS have significant intellectual impairment, females show a wider spectrum of cognitive abilities.

Floor effects have been reported when assessing children with FXS using the WISC-III (Hessl et al., 2009) ranging from 40 per cent (picture completion) to 70 per cent (arithmetic).
Individuals with FXS had been shown to demonstrate strengths in Verbal IQ relative to Performance IQ, with specific deficits in short-term memory for complex information relative to that for simple meaningful information and additional deficits in visuo-construction and visuo-spatial skills (Cornish, Sudhalter & Turk, 2004). Basic language skills including vocabulary are relatively spared and may be age appropriate in females with FXS (Lasker et al., 2007).

Van der Molen et al. (2010) investigated the cognitive profile in males with FXS. Their results showed that cognitive performance is particularly weak on measures of reasoning but relatively strong on measures of visuo-perceptual recognition and vocabulary. A significant weakness was found for verbal short-term memory. The pattern of results overall was interpreted to suggest a fundamental deficit in executive control.

In reviewing the literature Cornish et al. (2004) concluded that when using well-defined tests of attention (selective, divided, sustained attention) and working memory (phonological processing, visuo-spatial memory and executive capacity), FXS children, when compared to appropriate controls (typically developing children and children with DS), appear to have profound impairments in inhibitory control which are particularly apparent for skills that require switching from a response that has just been made to a new response in a sequence, whether the first response has been successful or not. They also identified a particular pattern of deficits in speech and language fluency, characterised by a greater incidence of repetitive and impulsive speech that appears to be specific to FXS.

Van der Molen et al. (2012) explored the ability of individuals with FXS to changing demands in the environment using the intra-extra dimensional set-shifting paradigm (IED) from the Cambridge Neurological Test Automated Battery. They found that compared to controls (children matched on ability level, adults matched on age and DS matched on ability level and age) a significant proportion of males with FXS had already failed prior to the intra-dimensional set-shift stage. They showed a specific weakness in reversal learning characterised by repetitive decision making, that is, responding to the same but incorrect stimulus. However, when the stimulus configurations became more complex, FXS males displayed increased distraction to irrelevant stimuli.

Klinefelter syndrome

Although there is a lowering of general cognitive ability, most individuals with Klinefelter syndrome do not have intellectual disabilities. There is a risk of language disorders and reading disabilities/dyslexia (Boada et al., 2009). Difficulties with verbal learning may arise from underlying deficits in auditory processing and verbal memory (Geschwind & Dykens, 2004). It is also associated with executive dysfunction; primarily difficulties with inhibition (Boada et al., 2009, Geschwind & Dykens, 2004).

Prader-Willi Syndrome (PWS)

A number of studies support a distinct pattern of cognitive strengths and weaknesses in individuals with a diagnosis of PWS. These include relative strengths in academic achievement (Whittington et al., 2004) and visual processing (Dykens, 2002) and weaknesses in auditory processing (Stauder, Brinkman & Curfs, 2002), mathematical skills
(Bertella et al., 2005) and short-term memory (Walley & Donaldson, 2005). Woodcock, Oliver and Humphreys (2009) found that children with PWS showed difficulties with switching attention. Spoken language (sometimes affected by hypernasality) is generally poorer than comprehension. A marked skill in completing jigsaw puzzles has been noted (Udwin, 1998).

Jauregi et al. (2007) found individuals with PWS scored significantly lower than the normative reference population on a number of measures of attention and executive functioning including verbal fluency (letter and category), trail making and Wisconsin Card Sort Test.

**Turner’s syndrome (TS)**

TS occurs only in females. Lasker et al. (2007) and Hong et al. (2009) both reviewed research looking at the neuropsychological deficits of individuals with TS. The global cognitive phenotype for TS includes only slight lowering of IQ with Verbal IQ scores typically exceeding Performance IQ scores.

While individuals with TS have good vocabulary and may know low frequency words (e.g. Assyrian, antediluvian; Temple, 2002) there are some deficits within verbal skills. Hong et al. (2009) conclude that overall there is evidence for verbal strengths in phonological and semantic processing but deficits in verbal fluency and syntactic processing particularly with regard to verbal content that recruits visual-spatial and executive domains.

Adults with Turner’s syndrome have good verbal memory skills; for example, their immediate story recall was found to be similar to, or higher than that of a control group (Bishop et al., 2000). However, they have difficulties with visual memory (Ross et al., 2002).

Executive dysfunction in girls with TS appears to be selective. It appears they may have difficulty inhibiting strongly prepotent responses and a lack of organisation in rapid retrieval of information, but intact skills in planning ahead to execute a strategy, and intact ability to shift response set (Hong et al., 2009; Lasker, 2007; Temple, 2002).

There is also some research suggesting difficulties in visual perception, visuo-constructional tasks and visual memory. Hong et al. (2009) conclude that timed tests may be difficult for individual’s with TS and that they struggle with tasks that combine visual functioning, executive abstract reasoning and mental flexibility.

**William’s syndrome (WS)**

Most individuals with WS have moderate to mild intellectual impairment but some may have low average to average abilities. In 2008, Martens, Wilson and Reuters reviewed the research on the cognitive, behavioural and neuroanatomical phenotype of WS. They concluded that language development tends to be typical, although delayed, with visuo-spatial difficulties confirmed across studies. However, they also emphasise the fact that variability still exists within the phenotype. Auditory rote memory and face processing skills appear relatively intact (Howlin, 2006) and individuals with WS perform particularly well on measures of forward digit recall (Mervis & John, 2010).
In their review of research on WS, Mervis and John (2010) suggest caution in interpretation of profiles on Wechsler tests. In one study only 24 per cent scored significantly higher on verbal composite score and one per cent scored significantly higher on the performance composite (Searcy et al., 2004). They also conclude that individuals with WS may have difficulties with more complex aspects of language such as relational/conceptual vocabulary and pragmatics.

Social disinhibition and inappropriate friendliness are characteristic of this condition (Howlin, 2006). Rhodes et al. (2010) investigated executive neuropsychological functioning in individuals with WS. Their results indicated that individuals with WS showed impaired executive functioning on tasks of attention set shifting, working memory and planning. Non-executive deficits were also observed on tests of short-term delayed memory and memory span. Mervis and John (2010) conclude that individuals with WS are better at verbal than motor inhibition.

These cognitive deficits are reflected in adaptive behaviour with relative strengths in domains that depend heavily on verbal skills such as social interaction and weaknesses in domains that depend on visuo-motor integration or spatial skills such as self-help and community living skills (Mervis & John, 2010).

**Factors that can impact on cognitive functioning/test performance**

A number of factors may influence an individual’s cognitive function and their performance on neuropsychological tests. These factors include:

- Motivation and effort;
- Fatigue;
- Epilepsy;
- Medication/use of drugs;
- Head injury;
- Physical and mental health;
- Motor/sensory impairments;
- Culture/diversity.

**Motivation and effort**

Neuropsychological tests are not valid if the individual being tested does not try hard on the tests (BPS, 2009). Individuals with intellectual disabilities will, by definition, have extensive experience of failure in all aspects of life, particularly academic tasks. It has been suggested that this can shape the approach of individuals with intellectual disabilities to new challenges: making them avoid new tasks, expect failure and look to others for cues as to how to solve problems (Zigler et al., 2002). This can undermine their ability to sustain effort independently. Assessors need to pay special attention to helping the individual to engage and persist with testing.

However, it is recognised (BPS, 2015b) that, in some circumstances, an individual thought to have intellectual disabilities may deliberately under-perform during a formal assessment (e.g. in an attempt to gain access to benefits, services or activities, or to avoid the criminal justice system). They recommend that, where this is suspected, the psychologist should consider and, where indicated, formally assess the individual’s effort throughout the assessment.
In this regard it is important to be aware that 'learning disability' is one of the exceptions identified to the recommendation of routinely giving effort tests as part of all assessments (BPS, 2009). This is because of the findings of Dean et al. (2008). In an examination of effort indicators in neuropsychology outpatients who were not in litigation or attempting to obtain disability they found that all patients with an IQ under 70 failed at least one effort measure. Those with an IQ of 60 to 69 failed 44 per cent effort indicators and those with an IQ of 50 to 59 failed 60 per cent.

**Recommendation**

Where assessment of effort is required this should be done in line with guidance in the British Psychological Society’s publication, *Assessment of Effort in Clinical Testing of Cognitive Functioning for Adults* (2009).

**Fatigue**

It is important to be aware of the potential impact of fatigue on individuals taking part in cognitive assessments.

*Fatigue can be caused by relatively long-term factors such as chronic mental or physical health problems, disabilities and associated medications, as well as by more immediate and fluctuating factors such as recent sleep disruption, poor nutrition or acute illness. It reduces test performance, so assessments should not be undertaken when it is suspected that a person is unduly fatigued. Psychologists should enquire – preferably from a third-party in addition to the person being assessed – about the individual’s level of fatigue. In addition, psychologists should remain alert throughout the assessment to other indicators of fatigue, such as a marked drop in performance or restlessness, and be prepared to pause or postpone the assessment as necessary*’ (BPS, 2015b).

This advice is equally applicable to a wider, neuropsychological assessment. Where longer term/chronic fatigue is identified, its impact on cognitive functioning will form an important part of the formulation and recommendations from the assessment. There may be circumstances where tests/observations might be carried out in different levels of fatigue to explore its impact on the individual’s functioning and hence increase the relevance of advice given in relation to their everyday functioning.

**Epilepsy**

Epilepsy is ‘a tendency of occurrence of transient recurrent abnormal electrical discharges in the brain, affecting one or more brain function…’ (Deb, 2007). Epilepsy is not a unitary disorder; its impact can come from the type of seizure, its treatment or the associated brain damage (Cull, 1997).

Seizures may be focal/partial or generalised. Focal seizures start in and affect one part of the brain (the ‘focus’); what happens during the seizure depends on the brain lobe affected. Simple focal seizures affect a small part of the lobe. The individual will be conscious throughout but have unusual experiences, for example, visual hallucinations for occipital lobe. In complex focal/partial seizures a larger area of one hemisphere is involved and consciousness may be compromised causing confusion. The individual may
cry out or make strange, repetitive movements. Generalised seizures involve both sides of the brain at once and generally involve loss of consciousness. These include absences (very brief loss of consciousness) and tonic-clonic (involuntary stiffness of the body followed by jerking/shaking). Myoclonic seizures comprise a brief muscle jerk without loss of consciousness; these often occur in clusters (National Epilepsy Society, accessed 2015).

It is important to be aware that the impact of epilepsy extends beyond the moment of the seizure itself. There may be changes to mood and behaviour in the period leading up to (prodrome) and after the seizure (post-ictal) the individual may be confused and tired. There may also be disturbances of consciousness in the period between seizures (inter-ictal) as a result of absences or sub-clinical seizure activity (Cull, 1997).

Cognitive impairments, particularly affecting memory and executive functioning may be found in individuals with epilepsy. Repeated absence seizures can affect learning.

Anti-epileptic medication can have unwanted effects. The effects will depend on the type of medication, the level of medication and whether polypharmacy is being used to reduce the frequency of seizures. The anti-epilepsy medications phenytoin and topiramate can affect cognitive functioning (Deb, 2007). Individuals with intellectual disabilities and epilepsy are more likely to have intractable seizures resulting in more polypharmacy and a higher risk of over-medication (Espie & Paul, 1997). Individuals with intellectual disabilities are also more sensitive to drug effects.

Reviewing the literature Deb (2007) concludes that individuals with intellectual disabilities are more likely to have epilepsy than the general population (14 to 24 per cent compared to 0.5 per cent) and that prevalence depends on age (increases with age), severity of the disability (the more severe the higher the rate) and whether there is an associated neurological disorder.

Some conditions which cause intellectual disabilities also bring an increased risk of developing epilepsy (Deb & Ahmed, 2000). For example:

- Down’s syndrome: Five to 10 per cent but increasing with age such that as many as 75 per cent of older individuals may develop epilepsy;
- Fragile X syndrome: 25 per cent epilepsy may develop with the onset of adolescence but the frequency tends to decrease with age;
- Rett syndrome: 75 per cent;
- Angelman syndrome: 86 per cent;
- Tuberous Sclerosis: 80 per cent;
- Lesch-Nyhan syndrome: 50 per cent.

Certain epilepsy syndromes are associated with intellectual disabilities including West syndrome and Lennox-Gastau syndrome.

Diagnosis of some seizure types, for example, partial or absence seizures, can be difficult in individuals with intellectual disabilities because of limitations of self-report and difficulties tolerating investigations, for example, EEG and video telemetry (Deb, 2007; NICE, 2012). It is important to be aware that some apparent seizures may not be the result of epilepsy as non-epileptic seizure disorders (pseudo seizures) have been identified (Deb, 2007).

There is NICE guidance on the assessment and treatment of epilepsy (NICE, 2012, CG137). The guidance recommends neuropsychological assessment should be considered
in ‘children, young people and adults in whom it is important to evaluate learning disabilities and cognitive dysfunction, particularly with regard to language and memory’. Assessment is also recommended where the individual is having educational or occupational difficulties, where cerebral MRI has shown abnormalities in cognitively important brain regions, where the individual reports difficulties with memory, other cognitive deficits or cognitive decline.

Medication

A wide range of medications can impact on cognitive functioning. This may be through the direct effect, a side-effect, as a result of over-medication or the effects of changes to the dose (Lezak, 1995). It is, therefore, important to record any medication taken, the dose and any changes to medication. The possible impact on cognitive functioning can then be explored. Detailed information on specific medications can be found by consulting the current version of the British National Formulary (British Medical Association and Royal Pharmaceutical Society).

Use of drugs/alcohol

The use of drugs/alcohol will impact on cognitive functioning in everyday life and performance in the test situation. This should, therefore, be carefully explored. See Lezak et al. (2012) for further information.

Head injury/concussions

Head injuries and repeated concussions may have resulted in brain injury/damage. Therefore, it is important to collect information about any that may have occurred.

Recommendations

It is important to collect as much information as possible about factors that may impact on cognitive functioning.

Where there is a history of head injury, or illness that may cause damage to the brain or there the individual experiences epilepsy it may be helpful to consult an expert in these areas.

Physical and mental health

Some illnesses can cause damage to the brain (Lezak et al., 2012). It is, therefore, important to take a full history of physical health.

It is noted that assessments carried out immediately before or after a woman has given birth are of questionable validity (BPS, 2015b).

The impact of mental health on the assessment of intellectual ability is discussed in BPS (2015b, p.19). In particular they highlight the impact of detention under the Mental Health Act on the validity and reliability of assessment.
Motor/sensory impairments

The WAIS-IV and WMS-IV manuals warn against attributing poor performance on tests to low intellectual ability when in fact some form of physical, language and/or sensory difficulties may be responsible. They recommend that when testing individuals with additional needs a battery of measures should be used, and that any adaptations from standardised administration procedures should be documented. Clinical judgement (see BPS, 2015b, p.22) should be applied to evaluate the effects of any such modifications on the scores obtained.

Many test manuals give specific advice on how that particular test may be adapted for specific impairments. For example, the WAIS-IV manual lists a number of issues that should be considered when testing individuals with hearing impairments.

Recommendations

When considering using a particular test with an individual with a motor or sensory impairment check the test manual for any specific advice on adaptation of administration and interpretation of results.

Culture and diversity

It is becoming increasingly common for psychologists to be asked to assess individuals who do not have English as their first language. The validity of such assessments can be problematic, for a variety of reasons (BPS, 2015b). Differences in language, culture and cultural expectations can make it hard to establish rapport. There can also be difficulties in relaying specific test instructions. Neither of these will necessarily be ameliorated by the use of interpreters and/or non-verbal assessment materials. Individuals educated abroad may have had limited educational opportunities and/or experience of formal assessments. This may make them suspicious or ill at ease in the test situation. Many tests have been shown to be culturally biased and/or have been normed and standardised with reference to just a single country’s population, such that individuals from other cultures or populations may be disadvantaged when presented with them.

Psychologists should, therefore, consider each of the following when carrying out assessments of persons from different cultural backgrounds:

- Recognise and acknowledge any cultural differences;
- Seek to offer a culturally sensitive environment;
- Conduct an initial, comprehensive clinical interview, in an attempt to understand any relevant cultural nuances and differences;
- Be aware of the potential difficulties in using interpreters (e.g. an interpreter may misunderstand and/or misinterpret instructions, providing either too little or too much information to either the examiner or the person being assessed);
- Highlight the above difficulties, particularly in respect of how they have impacted upon the interpretation of any test results obtained, in clinical reports.

These recommendations would equally apply to a wider neuropsychological assessment.
It should also be noted that some individuals born abroad may not know their date of birth. For many tests, age is essential to calculate the score. Without a date of birth it will be impossible to interpret the results of these tests. An incorrect date of birth may also distort the results.

Many test manuals give specific advice about the use of that particular test with populations outside the standardisation population.

**Test choice**

First choice is bilingual evaluation by bilingual person using test validated and standardised in individual’s first language. If this is not available then non-verbal tests should be considered (BPS, 2008).

**Use of interpreters**

In some situations, clinical need may mean that the clinician decides to administer tests through an interpreter. The clinician should then work with the interpreter in advance of the testing session to establish how this will be done. Tests should not be translated on the spot (BPS, 2008). Where tests have been translated, this constitutes a significant deviation from standard administration and is likely to mean that comparison of scores to the test norms is not valid.

Use of a signing interpreter to assist in assessment of individuals with hearing impairment is particularly problematic and results should be interpreted with extreme caution (BPS, 2008).

**Recommendations**

If the decision is made to work with an interpreter, it is important to follow recommendations on the use of interpreter (see BPS, 2008, Section 9).

Consult test manuals for test specific recommendations.

Where tests have been translated, results should be interpreted with extreme caution: it may be appropriate to only report qualitative information.
Section 3: Guidance

This section presents information on:

- Ethical testing;
- Information gathering;
- Identification of areas to be assessed/questions to be answered;
- Test selection;
- Setting up the test situation;
- Test administration;
- Scoring tests;
- Interpretation of results and formulation;
- Recommendations for therapy, rehabilitation and mitigation of deficits;
- Presenting and disseminating findings;
- Storage of test record forms;
- Outcomes;
- Service user evaluations;
- Reassessment.

Ethical testing

Capacity and consent

Consent to the information gathering stage should be sought in the same manner as for any piece of clinical work. Once it has been established that testing is necessary consent should be sought for the testing process. It is essential to discuss the purpose and process of the tests with the individual and how any results will be used. It should be clear to the individual that they have a choice as to whether they wish to undertake the tests. It is possible that the individual appears unable to consent to the testing process, but is able to complete some tests. Where the results of these tests may be clinically useful, a two-part capacity assessment should be completed (MCA, 2005). Where the individual is found to lack capacity, the issues should be discussed with others in their care network and a decision whether to proceed made in their best interests. All discussions should be documented in clinical case notes, in the report and on relevant ‘Best Interest’ record forms. Appendix 1 gives a consent form for completion of IQ tests/neuropsychological tests which can be completed with the individual prior to testing and stored in the clinical case notes/electronic records as appropriate. Appendix 2 gives an accessible, easy read information leaflet about cognitive assessments that can be used to facilitate the consent process.

Confidentiality

As part of obtaining consent for the assessment it should be agreed who the results will be shared with and for what purpose. The limits of confidentiality should also be explained (e.g. procedure and circumstances for disclosing issues of risk, discussions with supervisor, written case notes). Where the assessment is being carried out on the basis of best interest this process should also be applied to the decision as to who should receive a copy of the report.
Emotional distress

It is important to be aware of the impact that testing may have on an individual. The failure that is a key part of neuropsychological testing can be emotionally painful for some people. Others may be distressed by the outcome of the assessment. Attention should be given to planning the administration of tests and feedback process to minimise the risk of emotional distress. The wellbeing of the individual must always take priority over the requirements of the testing procedure. Testing must be stopped if the individual withdraws their consent at any time or becomes unduly distressed.

The idea of testing and the assessment process may also cause anxiety and distress in people close to the individual such as family members/carers and staff. Thought should be given to the impact of the assessment on the wider system and how this can be minimised.

Recommendations

The process used to seek consent to neuropsychological assessment and testing must comply with the Mental Capacity Act (2005).

The wellbeing of the individual must always take priority over the test requirements.

Information gathering

It is important to begin by gathering as much information about the individual and their problems before undertaking any formal assessment.

Such information should give:

- A clear picture of the presenting problem;
- A check that possible physical causes for the problem have been eliminated;
- A rationale for the assessment and selecting tests;
- A base line of previous levels of functioning;
- A context for interpreting results;
- Information about any issues to be taken into account in planning the assessment;
- Information about any issues to be taken into account when interpreting the results.

Medical information may be helpful in ruling out physical causes for any reported changes in behaviour or cognition. If no recent health checks have been carried out, these should be requested. These might include; thyroid functioning or eyesight and hearing tests (see BPS, 2015a, for more detailed information).

Every effort should be made to collect information that will help with the selection and interpretation of tests. This includes:

- Accurate date of birth;
- First language and any other language spoken;
- Education history – with as much detail as possible as to the type of school attended and any qualifications taken;
- Cultural background;
- Significant illnesses, head injuries or accidents, physical or emotional trauma;
- Sensory and physical impairments including whether the individual needs/uses spectacles or hearing aids;
Presence of epilepsy, types and pattern of seizures experienced;
Presence of conditions such as ASC, mental health problems, etc.;
Specific syndromes;
Current medication;
Use of drugs/alcohol;
Recent changes in behaviour, health, medication, circumstances/life events experienced;
Any previous assessments, tests used and results.

It is helpful to use a range of sources including:
- Interviewing the individual;
- Observing the individual;
- Interviewing carers, family members or staff and independent advocates;
- Reviewing previous reports.

Speech and language therapy reports are particularly helpful in identifying the tests an individual is likely to be able to complete. Occupational therapy reports may be helpful in providing detailed information about adaptive functioning and sensory profiles. Psychiatric reports may be helpful in exploring the impact of mental health problems on performance.

Historic reports from all professionals may be helpful in establishing previous levels of functioning where deterioration is suspected.

**Recommendations**

Physical health screening should be undertaken prior to neuropsychological assessment.

Thorough information gathering must be undertaken prior to assessment to facilitate the correct selection of tests and interpretation of results.

**Identification of areas to be assessed/questions to be answered**

The rationale section in the introduction lists possible reasons for neuropsychological testing. The information gathering process should have clarified the specific questions being asked about the individual being assessed. It is important to be alert to different people having different questions/expectations of the assessment. Once the questions being asked have been explicated it is then necessary to identify what areas of cognitive functioning need to be assessed to answer those questions.

Consider which of the following are needed:
- Overall level of cognitive functioning;
- Profile of general cognitive skills;
- Profile of skills in specific areas, for example, memory or executive function;
- In-depth exploration of specific areas;
- A baseline for monitoring future changes;
- Comparison of functioning at different points in time;
- Comparison of test results with functioning in everyday situations.
**Test selection**

The choice of which tests to administer will depend upon:

- The question to be answered;
- Characteristics of the individual;
- Characteristics of the tests;
- Practical issues;
- Professional issues.

*The question to be answered*

The tests necessary to answer the assessment questions should be self-evident. If this is not the case the questions should be revisited to make them more explicit.

When looking for changes in functioning it is usually most helpful to repeat whatever tests/version the individual completed previously as this allows the most accurate comparison. If, however, the individual scores near to the floor of the repeated tests, it may also be appropriate to administer a test assessing the same skills but with a lower floor. This will then allow more accurate measurement of any future deterioration.

Where the need for re-testing is anticipated, the impact of practice effects should be considered. In this situation tests with parallel forms may be the most appropriate choice.

*Characteristics of the individual*

Clinicians need to consider a number of individual characteristics when selecting tests including:

- Age;
- Apparent level of ability;
- Method of communication;
- Language comprehension;
- Levels of literacy and numeracy;
- Ability to engage, for example, attention span, motivation;
- Processing speed/response times;
- Physical and sensory impairments, for example, ability to manipulate materials, colour blindness, visual impairment, hearing impairment;
- Presence of condition with known cognitive profile/phenotype.

*Apparent level of ability:* The aim in selecting tests is that the individual will be able to score on the majority subtests. Section 4 lists some tests and indicates the range of ability for which they are most useful.

*Method of communication:* It is important to select tests that allow the individual to understand the questions and communicate their answers. This presents a particular
challenge when the individual does not speak English, where English is their second language or where the individual communicates through sign language (see ‘Diversity’ in Section 2: Context).

**Engagement:** Where an individual is reluctant to participate or has a very limited attention span it is important to balance the richness of the results of a test against the likelihood that the individual will complete the test. It may be appropriate to choose a less demanding test that someone is likely to complete in preference to a more comprehensive test that they may not be willing to attempt or may fail to complete.

**Colour vision:** Clinicians should be conscious of the impact of colour vision on the choice of assessments. It is important to check colour vision as individuals and their carers/staff may be unaware that the individual lacks full colour vision. A simple screen for this can be done by asking the individual to identify/point to or match the colours of the blocks from the Leiter International Performance Scale, or the cards from the Colour Form Sort.

**Cognitive profiles:** Some conditions may present with characteristic patterns of neuropsychological functioning (cognitive profiles/cognitive phenotypes) for example, William’s syndrome. Information on these patterns may be helpful in the selection and interpretation of tests. The cognitive profiles associated with some of the more common syndromes are outlined in Section 2: Context. However, this is a rapidly developing field with new genetic disorders being identified. Where the individual has a known disorder it is good practice to check recent literature for newly identified cognitive patterns.

### Characteristics of the tests

Section 4 describes a range of batteries and individual tests that may be helpful in assessing different areas of functioning in individuals with intellectual disabilities.

The complexity of assessing this population means that it is not appropriate to recommend specific tests. Rather there are a number of test characteristics need to be taken in to account. These include:

- Standardised or non-standardised;
- Normative data;
- Floor effects;
- Single tests or part of a test battery;
- Test versions/edition.

See also Lezak (1995) for a discussion of reliability/validity and test specificity within a neuropsychological context.

**Standardised and non-standardised tests:** Standardised tests have manualised instructions, have been given to a selected sample of the relevant clinical population and provide norms that allow comparison with that population and will have data on reliability and validity. This is time consuming and expensive process. It is also particularly challenging when the clinical population is individuals with neuropsychological problems (Lezak, 1995). Standardised tests have the advantage of known reliability/validity and allow comparison with the others. Standardised tests are generally available for frequently asked questions in the general population, for example, general cognitive ability or memory.
In contrast, non-standardised tests lack some or all of the following: manualised instructions, data from a normalisation sample and information on reliability and validity. These tests have often evolved from clinical practice or research. They often assess aspects of functioning not addressed by standardised tests or are usable by populations who cannot achieve meaningful scores on the (usually more difficult) standardised version.

Where there is a choice of tests that the individual is likely to be able to complete, it is generally appropriate to select the standardised test.

**Normative data**: When choosing and administering tests with individuals with intellectual disabilities, it is important to look at the relevant manual in order to determine whether the normative data can be applied to the individual being assessed. Where a test has limited/no normative data for people with intellectual disabilities, it may still be used, but the results should be interpreted with caution and this should be highlighted in the final report.

Where there is a choice of tests, the one with the most relevant norms is likely to be the test of choice.

**Floor effects**: Many neuropsychological tests may only be appropriate for use with individuals with mild/significant intellectual disabilities; they are likely to be too difficult for individuals with more severe intellectual disabilities. Clinicians need to be aware of ‘floor effects’ when choosing tests for individuals thought to have more severe intellectual impairment. If the tests are too hard for the individual to complete, they will not be able to score on the test. In these situations, it is not clear whether an individual has failed a task because they have a specific deficit or simply as a result of the test being too difficult given the individual’s level of intellectual impairment. These difficulties arise particularly for tests that rely on complex verbal instructions and/or require the use of complex vocabulary/language. In these cases, observations of the client and the use of non-standardised tests may be more appropriate (see below for further details).

**Single tests vs. test batteries**: Many tests have been developed to look at specific neurological functions, for example, Memory for Figures. Sometimes a number of these tests have been brought together to form a battery of tests looking at different aspects of one area of functioning, for example, memory. The use of a test battery allows for a wider assessment. Such batteries have often been normed on a single population, allowing comparison across subtests. The use of individual tests may allow assessment of areas not included in test batteries. It may also reduce testing time and minimise fatigue when only one area of functioning is of interest.
Psychologists should be careful that the tests selected are sufficiently wide-ranging to thoroughly assess the issues of concern and ensure that any possible deficits are identified.

Test version: There are sometimes multiple versions of tests. Newer versions of tests may include updated norms, changes to test administration and new subtests. Other subtests may have been deleted. Sometimes changes can make tests more usable for people with intellectual disabilities. This is the case with the changes made from with WAIS-III to the WAIS-IV (Whitaker, 2012). However, they may also make the test less usable for this population. BPS guidance (2015b, p.16) recommends that only the most recent versions of measures should be used. However this advice is given in the specific context of diagnosing intellectual disability. For a wider, neuropsychological assessment, it is important to weigh up the benefits of recent over older versions of any particular test and not assume that the most recent version is automatically the most appropriate to use.

Some tests have parallel versions that allow for retesting. These may be helpful where there is rapid change or the risk that one administration might be spoilt. When using parallel versions it is important to be aware that practice effects may occur if the elapsed time between testing sessions is short.

Recommendations

In neuropsychological testing, clinical judgement should be used to determine if the need to obtain important clinical information over-rides the imperative for using the most recent norm-referenced test that applies in a purely diagnostic assessment.

Where this is the case the rationale should be recorded in the clinical report.

If using tests with parallel versions, check the manual for advice on the minimum time between administrations and the impact of practice effects.

Practical issues: There are many tests available from a number of test suppliers. Most tests are very expensive, but many might only be used rarely. Consequently it is likely that most assessors will have access to a limited number of tests.

Collecting qualitative information (often the most valuable part of an assessment) is only possible where the assessor is fully familiar with the test materials. The selection of tests should, therefore, also consider the availability of test materials and the assessors experience in using those materials.

Recommendation

Test selection must take into account the questions to be answered, the characteristics of the individual and the characteristics of the tests available and the experience of the assessor.
Professional issues: The assessor should ensure that they meet the criteria required by the publishers and distributors of any tests they are planning to use (BPS, 2015b).

**Recommendation**
Tests should only be used when the assessor meets the criteria required by the publishers and distributors of that test.

Setting up the test situation
There are a number of factors to consider in setting up the testing situation. These include:
- Safety;
- Presence of others in the test situation;
- Ensuring the individual is prepared;
- Structuring the testing process.

**Safety**
Risks may arise as a result of known behaviours that challenge or as a result of the demands of the test situation. Risks should be identified and management strategies put in place.

Completing cognitive assessments can be stressful for the individual. Thought needs to be given to how to minimise this distress, for example, reassuring the individual about their performance. It is also important to consider how to keep both the individual and clinician safe if the individual has a strong reaction. This might be achieved by carrying a personal alarm or having another person present (but see section below on the impact of others on the assessment).

Consideration should be given to the layout of the room and position of the furniture, the time of day the assessment will take place and the availability of other staff within the building. Lone working procedure should be followed if the individual is being observed or assessed at their home.

**Recommendation**
Where there is a conflict between ideal conditions for testing and safety considerations safety must take priority.

Presence of others in the test situation
There are a number of reasons why others may be present in the test situation:
- To support and reassure the individual;
- To support/protect the assessor;
- To observe the assessor or the assessment process.
To support/reassure the individual: It may be useful to have carers/family members or staff present when the purpose and nature of the tests are explained to the individual. However, it is preferable not to have others in the room when the tests are being completed, as this may make the individual more anxious and/or they may find it difficult not to help/coach the individual. If there is no acceptable alternative, it needs to be carefully explained to the carer, family member or staff that they should not help or interject in any way. It may help to seat them out of the individual’s sight to minimise the chances of them giving non-verbal help to the individual.

To support/protect the assessor: Where the individual poses a risk to the clinician, safety considerations should override the potential impact on the assessment results.

Staff present to protect the assessor need to be fully briefed about the assessment process and be asked not to help the individual or interact with the assessor unless it is related directly to their safety. In this situation the individual’s consent is not sought for the observer to be present. Rather consent is sought for participation in an assessment with another member of staff being present.

Observation of the assessor/assessment process: Observation of some cognitive assessments and being observed administering such assessments are requirements for clinical psychology trainees. Observation is also beneficial experience for other professionals in training, for example, nurses, psychiatrists, speech and language therapists.

Consideration should be given as to whether the observation for teaching purposes could be achieved by other means for example the use of video or audio recording. For example, if the WAIS-IV is administered by iPad, there is an option to audio record the session. Where this approach is taken the necessary consent needs to be obtained and the safe use, storage and disposal of the recording need to be addressed.

Consent must always be sought for an assessment to be observed. The psychologist leading the assessment should ensure that the individual understands what the observer will be doing and that the room is arranged so that everyone is safe and comfortable. The psychologist must use their clinical judgement to decide if the observer is having a negative impact on the assessment. If this occurs the needs of the individual must take priority over the training needs of the observer.

Observation of the assessment offers some potential benefits for the individual. The observer may notice fine details of performance that may be missed by the test administrator as a result of the demands of administration. The individual may also gain a sense of worth from contributing to the training of a professional and hence potentially benefiting many other people.

Impact of observers on the assessment/outcome: It should be noted that, if the presence of a third party has a negative effect on performance, then this could affect the validity and interpretation of test scores (Committee on Psychological Test and Assessment American Psychological Association, 2007).
**Ensuring the individual is prepared**

It is important that the individual arrives at the testing appointment able to give their best performance. The assessor should ensure that the individual brings with them any spectacles, hearing aids or communication aids used and that these are in working order. It is also important to check that the individual is physically comfortable, for example, by offering a drink, showing them where the toilet is and ensuring they are neither too hot nor too cold.

**Structuring the testing process**

Consideration should be given to the best environment to complete the tests. Ideally the environment should be free from distractions and interruptions. It should be furnished (table, chairs, adequate lighting, blinds/curtains, heating/ventilation) to complete the test in comfort. Generally it is most appropriate to complete tests in an office environment. There may be exceptions to this, for example if the individual has severe mobility problems or is extremely anxious then it may be better to complete the test in the individual’s home.

**Timing, breaks, length of sessions:** The length of any testing session needs to be considered in light of an individual’s attention span and fatigue levels. It is unlikely that anyone with intellectual disabilities would be able to concentrate for much more than one hour. Regular breaks should be offered throughout any assessment. It may also be necessary to spread subtests of a test battery over a number of sessions. Particular thought should be given to planning memory tests as these often need to be completed within a set timeframe. Spreading testing across more than one session generally constitutes a deviation from standard administration and should be noted and discussed in the report.

**Length of assessment:** This will depend on the number and type of tests chosen and the purpose of the assessment. The time taken to administer each test can vary considerably depending on the individual’s ability levels, fatigue, etc. Where possible, assessment sessions should be completed within a compact time frame (e.g. four to six weeks) in order to maximise the validity of the results. Details of the time frame of the assessment and any implications for the interpretation of the results should be noted in the report.

**Test materials:** Materials needed are described in the individual test manuals or, where these do not exist, in the source reference. A good additional source of information about test materials is provided by Spreen and Strauss (1997, 2006).

It is important for the smooth running of the testing session that materials are all easily accessible, in the correct order and that no pieces are missing. Checking and sorting materials should be carried out prior to testing to avoid any disruption to the testing.
**Test administration**

*Standardised administration*

Most tests provide a manual outlining the standardised administration of the various tasks so that the scores obtained are reliable and valid. Complying with the standardised administration is essential when the purpose of the testing is to compare the individual’s performance with that of the standardisation sample (i.e. comparison with test norms).

*Non-standard administration*

There is always a balance to be struck between standardised administration of a test and/or gaining more clinical useful information by deviating from the standardised procedure. For example an individual may consistently fail timed items by being too slow, but successfully complete them if given extra time. Non-standardised administration may be considered in order to prevent the testing experience being too negative for the individual or to maintain motivation. Changes may also be made to compensate for communication, physical or sensory difficulties that make standard administration impossible. Possible factors to consider are whether to:

- Start at the first item or whether to use the ‘reverse rule’ (not applicable if using WAIS-IV);
- Continue to the defined cut off criteria for any given test or discontinue early to maintain motivation/minimise fatigue;
- Allow the individual to continue past the time allowance to see if they can complete a task;
- Change the test instructions to ensure the individual has understood the task;
- Encourage the individual to check for and correct errors;
- Giving additional encouragement to attempt tasks or to try a guess;
- Spreading subtests of test batteries over more than one testing session.

These types of decisions need to be based on clinical judgement, taking into account the presentation of the individual and the purpose of the assessment.

**Recommendations**

Where a test has been administered in a non-standardised way then this needs to be recorded on the test proforma and in the clinical report.

Within the clinical report a comment should be made as to why this was done and how the deviation from standardised procedure may have affected the individual’s score.

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**Recommendation:**

The testing situations should be carefully planned to maximise the chances of the individual performing at their best.
**Computerised test administration**

Tests are increasingly available for administration using a computer or iPad. These approaches to administration may be helpful with individuals who find interacting with the assessor difficult.

**Observation during testing**

Qualitative information from a neuropsychological assessment can provide much useful information. Careful observations during an assessment can provide information on:
- personal care and hygiene;
- appropriate choice of clothing and ability to present an acceptable appearance;
- ability to interact in an assessment situation;
- how the individual approaches different tasks;
- whether they work systematically, chaotically or in an unusual way, for example, working right to left;
- whether they are impulsive, rushing to respond, or slow and thoughtful;
- whether they persevere when things are difficult or ‘give up’ easily;
- whether they respond to encouragement;
- whether they are willing to have a guess or say ‘don’t know’;
- whether they check their performance and correct errors;
- whether they have any sense of how well they are doing and how they react to this emotionally;
- what helps them perform better;
- whether there are any absences/losses of consciousness.

This type of information can only be gained once a clinician is sufficiently familiar with the test administration and manual to spend time during the assessment observing the individual. Where a clinician is less experienced it can be very helpful to have a well briefed observer who can focus on these aspects, while the person administering the test concentrates on the correct administration (but see above for the implications of assessment being observed or to record the assessment session).

**Recommendation**

Qualitative information can be as, if not more important than test scores in answering questions. Collecting this information is an essential part of the testing process.

**Scoring tests**

Care must be taken in scoring test results, both to ensure that the correct score is given to each answer and that these scores are correctly added up. It is important to be aware of potential bias when scoring, for example, consistently giving the higher of two score options.

Timing is often an issue for individuals with intellectual disabilities. Where it appears that slowness is pulling down an individual’s scores it may be helpful to score twice. Firstly strictly according to the manual and then looking at how they would have scored if they...
had been able to complete items within the time limit. The second scores may be helpful in exploring optimum functioning and may help with understanding the issues faced by the individual. Where this approach is taken great care must be taken in reporting the results to avoid any misunderstandings by those reading the report.

Care must also be taken when converting raw scores into standard scores, indices and composite scores and in calculating difference scores. The assessor must be alert to differences between component tests that may make composite scores invalid.

Consideration should also be given to recognised alternative ways of scoring a particular test, for example, the approach to scoring the WAIS-IV advocated by Lichtenberger and Kaufman (2009).

**Computerised scoring systems/report writers**

Computerised scoring systems can be purchased for some tests including the WAIS-III and WAIS-IV and are inbuilt in tests administered electronically. However, care should be taken when using these, as the computer programme may calculate scores in situations where the technical manual advises they should not. For example, if an individual fails to score on the recommended number of WAIS subtests the computer programme will still calculate an overall index score when the manual advises against this.

**Recommendation**

Care must always be taken that tests are correctly scored and that only valid scores and composite scores are reported.

**Interpretation of results and formulation**

Simply scoring results is not sufficient: the most helpful outcomes of neuropsychological assessment are the interpretations given to the scores.

‘The examiner’s role in assessment is more than simply examining the scores: rather he or she must bring together research knowledge, theoretical sophistication, and solid clinical skill when interpreting tests’ (Lichtenberger & Kaufman, 2009, p.106).

It is also important to remember that interpretation is not simply about the final scores of a test but about all the information gathered during the assessment process. It is important to look at each level of the test: item, subtest, index/cluster and overall composite scores (McCloskey, 2009).

Each individual will be unique; however, the following questions may be helpful in exploring the implications of test scores:

- Did the individual fully understand the tasks and respond to the best of their ability? If not, why not?
- What might be the possible impact of factors such as medication, physical and mental health, fatigue, motivation and effort?
- How might significant events/experiences in the individual’s past have impacted on their test performance, for example, a history of head injury or substance misuse?
Do the results on tests measuring the same or similar functions agree? If not, why not?

Where there are inconsistencies, is it possible to construct a hypothesis as to why this might be so, and test this out in some way?

Are failures on tests due to difficulties with the skill the test is intended to measure or are they the result of lacking a secondary capacity not explicitly assessed, for example, poor visual acuity affecting performance on perceptual reasoning tasks? (see McCloskey, 2009).

How does the result on a given task compare with the results on the WAIS-III/IV, the LIPS, or the Raven’s Progressive Matrices? Do the results indicate a specific cognitive difficulty?

Do the results of tests fit with the observations or concerns highlighted already? Do they account for the problems the individual has been experiencing? If not, why not? Keep in mind the influence of other important factors such as social and emotional processes and social and practical knowledge (Channon, 2004).

Do the results fit the pattern of recognised organic/developmental conditions, for example, Korsakoff syndrome?

How does the profile of strengths and weaknesses compare with that found in the research literature for any specific condition the individual may have?

What are the implications of the results for the individual’s everyday functioning? What types of tasks/activities are they likely to find difficult?

How did the individual perform on this occasion compared to any previous testing? What are the relevant factors to any observed change in functioning?


The answers to these questions should be drawn together into a formulation which meets the standards in the BPS guidelines on the use of psychological formulation (2011b). In particular it should be remembered that the main purpose of a formulation is identifying the best way forward and informing the intervention (BPS, 2011b, p.8).

**Recommendations**

Interpretation should be sophisticated: taking into account all the information gathered, not simply test scores.

Formulation should meet the standards recommended by the BPS (2011b).

Where there is discussion about the presence or extent of an intellectual disability this should conform with the advice given by the BPS (2015b).
Recommendations for therapy, rehabilitation and mitigation of deficits

The interpretation and formulation of the test results should lead to specific recommendations that are integrated into care plans. Where an individual shows behaviours that challenge the results should also contribute to their Positive Behaviour Support Plan.

The completion of a neuropsychological assessment should not be the end of the process. There will usually be a number of tasks to be completed including:

- Explaining and educating the individual and those who support them about the nature and implications of the deficit;
- Identification of relative cognitive strengths or other positive or protective factors and strategies to maximise these;
- Identification and implementation of remedial or compensatory strategies;
- Identification of the implications for the individual’s support package.

While the psychologist may not carry out all of these tasks it should be clear who will be undertaking this work and how it will be followed up and evaluated.

Where problems are neuropsychological in origin, it is unlikely that any therapy approach alone will be effective. This is particularly true for individuals with executive problems who can often learn skills, but fail to apply them to their everyday life as appropriate, unless prompted. Therefore, recommendations may focus on adapting an individual’s environment to compensate for any identified cognitive difficulty.

Some general recommendations are outlined below.

**For memory difficulties:**
- Diaries, timetables, planners;
- Lists;
- Picture cue cards;
- Visual reminders;
- Use of alarm clocks/mobile phone apps;
- Labels/pictures on doors, cupboards, etc.

**For executive problems:**
- Provision of clear boundaries and feedback;
- Use of structure and routine;
- Clear statements of acceptable and non-acceptable behaviours including social stories;
- Written/visual procedures;
- Use of external contingencies;
- Flash cards of what to do and when;
- Flash cards of who to ask for help.

**For visual and perceptual problems:**
- Clearly delineating areas or objects by colour;
- Clear boundaries between walls and floors, and between steps on stairs;
- Signs or symbols on doors;
- Use of highlighters.
See Rehabilitation of Neuropsychological Disorders (Johnstone & Stonnington, 2009) for more detailed suggestions. It may also be helpful to seek supervision/advice from a neuropsychologist and/or occupational therapist.

**Recommendations**

Neuropsychological assessment should lead to recommendations that are integrated into the individual’s care plans/positive behaviour support plan. Advice from a neuropsychologist and/or occupational therapist may be helpful in planning interventions.

**Presenting and disseminating findings**

For a neuropsychological assessment to meet the needs of the individual it must be effectively disseminated. Dissemination will include face-to-face feedback and writing reports to meet the needs of different audiences. In some situations teaching may also be necessary, to give the individual or their carers/staff the information necessary to make sense of the findings.

**Feedback**

Wherever possible, the individual should be provided with individualised feedback on their test results, what they mean and what will happen next. This should be done verbally and in the form of an accessible report (see below). If this is not thought appropriate, the reasons for not providing feedback should be documented in the clinical notes.

Provided the necessary consent has been obtained, providing feedback to carers/staff is also vitally important.

**Report writing**

The format of the report and the amount of detail given will be influenced by the reason for the assessment and the audience likely to read the report. It is likely that two reports will be required; an accessible report for the individual and a more formal clinical report for other professionals.

Accessible reports: Accessible reports must be individualised. Individuals will vary as to whether they simply require information in short, clear sentences or need the support of symbols, line drawings or photographs. What is accessible for one individual may appear patronising or childish to another. Be careful not to include any specific questions from the tests administered as this would be a breach of copyright.

It is recommended that, wherever possible, an accessible report is devised in collaboration with the individual. Collaboratively writing the report allows the assessor ensure that the format used is genuinely accessible to the individual and also to check that the individual has properly understood the findings.
**Clinical reports:** Appendix 3 gives some recommendations on areas to be included in the clinical report. See also BPS (2015b).

It is important that the report contains a good summary/conclusions section as this will protect the individual from the risk that those supporting them may only read this part of what is, often, a lengthy document.

It is also essential that the report contains a clear recommendations section.

There are risks that the findings of neuropsychological testing may not be understood at all or that they may be misunderstood and misinterpreted. Two factors are important in preventing this:
- Relating test results to everyday life;
- Cautious and thoughtful presentation of test scores.

*Relating test results to everyday life:* Whilst the results of neuropsychological tests are useful and meaningful to psychologists and other clinicians they may be difficult to interpret and relate to everyday life for non-psychologists. Therefore, it is important in the clinical report to provide everyday examples of activities the individual may find difficult, use the results to help explain current concerns and behaviours and to help carers staff and members of the wider system, understand what the effect of any identified difficulty is likely to be. It may also be helpful to explain why certain interventions are likely to help; interventions for deficits may not fit with ‘common sense’ understanding and may not be followed if they do not make sense to carers/staff.

*Presentation of results:* There is a risk that the scores presented in neuropsychological reports may be misunderstood and misunderstood by non-psychologists (e.g. mistakenly being used to deny someone access to a service or interpreting small changes as indicating an increase or decrease in ability).

'It is a matter for individual psychologists to decide on the level of detail with which to present test results. However, the Society is mindful of a tendency amongst non-psychologists in particular to misinterpret the results of psychometric assessment measures presented in the form of single, standardised scores (such as IQs). The Society, therefore, strongly recommends that neither individual IQ scores nor their equivalents in respect of adaptive behaviour measures should be cited in psychological assessment reports. If test scores are deemed to be necessary, they should be reported not as single figures but as ranges of scores (e.g. ‘within the range 67 to 77’), in accordance with the statistical properties of the specific tests that have been used and with details provided of the probability (generally either 90 per cent or 95 per cent) that the person’s ‘true’ scores fall within the specified ranges.’ (BPS, 2015b, p.28)

However, access to the actual scores may be needed. For example, another psychologist may need to form their own opinion of the results or to meet the requirements of the courts. It is, therefore, good practice to have an Appendix of scores that is kept ONLY in the psychology file.

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**Recommendations**

Dissemination of the results of a neuropsychological assessment is essential and will usually go beyond a clinical report to include accessible reports and education.

Presentation of results in reports should comply with (BPS, 2015b).
**Storage of test record forms**

Thought should be given to the safe and confidential storage of the test record forms/proformas. These contain information that will be invaluable if re-testing is required. For example, the exact words of responses, patterns of failure and samples of handwriting (e.g. having written own name on form or completing coding tasks) may highlight subtle changes that might not be obvious from changes to overall scores.

**Outcomes**

The results of neuropsychological tests can be analysed quantitatively and qualitatively. As noted earlier, caution should be taken in how the results are interpreted, presented, disseminated and stored. Feedback could be sought from those supporting the individual to check that the assessment answered the referral question.

Assessment should not be an end in itself but should lead to specific recommendations to address the issues that lead to the referral. Consequently it is important to follow up the impact of the recommendations from the report.

**Service user evaluation**

The authors have been unable to find any information on the views of people with an intellectual disability in this area. However, some work has been carried out within neuropsychology services to seek the views of individuals about the assessment experience. This suggests that individuals find the process of assessment and feedback beneficial in understanding the problems they are experiencing (Blake, 2004).

**Reassessment**

Individuals may be referred for reassessment despite a comprehensive assessment having been carried out previously. Re-assessment should only be carried out where there is a valid clinical reason. Further assessment may be appropriate in certain circumstances. These include:

- Where there is evidence that the individual’s skills have deteriorated and this needs to be quantified. Practice effects can have a significant impact on test results. Before re-administering a test check the manual for the recommended minimum test-retest interval. Where none is given a minimum of six months is suggested.
- Where a different question has arisen that cannot be answered from the previous assessment, for example, the individual was assessed for memory deficit but there are now concerns about executive functioning.
- An event has occurred that may have impacted on cognitive functioning, for example, accident, illness, stroke (note in these circumstances assessment should be undertaken by/under the supervision of a neuropsychologist).

It is suggested that reassessment should not be carried out where:

- There is no evidence of change in function or need.
- Assessments purely for administrative purposes without evidence of clinical need.
Where re-referrals arise because previous advice has not been followed, the problem arising from the identified deficits persist because the person does not have the appropriate support package or where staff have not been trained to meet the person’s needs the referral would not be accepted. However, the psychologist has a responsibility to highlight these deficits. If these are not rectified the psychologist has duty to report the situation to the responsible authorities (for more information see description of ‘clinical advocacy’ in Challenging Behaviour: A unified approach, Royal College of Psychiatrists, British Psychological Society and Royal College of Speech and Language Therapists, 2007).

**Recommendations**

There should be clear, clinical grounds before any reassessment is undertaken.

The possible impact of practice effects should be discussed in the report.

Where previous recommendations have not been implemented the clinical psychologist has a duty to take action as a ‘clinical advocate’.
Section 4: Tests

This section presents information about some of the more widely available tests. It is not intended to be comprehensive and omission from this list does not mean that a test is unsuitable for use with individuals with intellectual disabilities. See section 3: Test selection, for guidance on choosing the most appropriate test for a particular assessment.

Tests of general intellectual ability

Wechsler Scales

The Wechsler Scales have been revised and updated a number of times over the last 70 years to incorporate advances in intellectual assessment and to update the normative data to reflect changes in the population. These developments are described in Lichtenberger and Kaufman (2009). The most recent version is the WAIS-IV, which was released in 2008 and came into use in the UK in 2010.

The WAIS-IV continues to provide a measure of general intellectual functioning (FSIQ) and a profile of component abilities through the four index scores: Verbal Comprehension, Perceptual Reasoning, Working Memory and Processing Speed.

As a result of the relative newness of the WAIS-IV there is a limited evidence base for its use with individuals with intellectual disabilities. Research with the previous version (WAIS-III) identified a number of issues. Whitaker (2005) highlighted the need to consider the following when interpreting results; the degree of difficulty of the test items, the use of American English, the difficulty of the verbal instructions, and the floor effects of the test.

McKenzie et al. (2004) explored the differences and adaptations used by clinicians when administering the WAIS-III to people with intellectual disabilities. The most frequent changes included omitting some subtests and changing the standardised instructions. The reasons given for these adaptations related to the complexity of some of the instructions. McKenzie et al. (2004) note it is unknown what effect these changes have on the scores obtained by individuals.

The WAIS-IV appears to have gone some way to address these concerns. The long and complicated instructions have been reduced although not eliminated (Whitaker, 2012) and the test is easier and less time consuming to administer and probably more user friendly for people with intellectual disabilities. There is still a concern, however, around scaled scores of one being derived from very low raw scores or raw scores of zero (Whitaker, 2012). It also has also been noted that test retest reliability may be lower in this range and may lead to greater variability in scores (Whitaker, 2012).

The WAIS-IV is the first choice test of general ability in individuals with significant intellectual disabilities. However, it should be used and interpreted with caution in individuals with more severe disabilities because of the impact of the floor effect.
Leiter International Performance Scales

The Leiter (LIPS), the Leiter International Performance Scale – Revised (LIPS-R) and Leiter International Performance Scale –Third Edition (Leiter-3) are non-verbal tests that may be useful for assessing general intellectual ability when an individual has limited verbal communication.

The block and frame format of the LIPS tasks can be less intimidating than the WAIS-III/WAIS-IV. The LIPS can facilitate engagement in individuals who may be reluctant or refuse to complete the Wechsler Scales. It can give useful qualitative information about an individual’s approach to tasks. The Leiter is normed on children from a particular geographical area and these norms are now very old, hence the results need to be interpreted with caution. The results of the test may provide useful information about an individual’s developmental stage, although these need to be reported carefully and in the context of an adult having had significantly different learning opportunities compared to a child.

The LIPS-R has an age range of 2 to 20 years. The administration of the LIPS-R is complex: It does not use the block and frame format. It is complex, having 20 subtests organised into four domains (reasoning, visualisation, memory and attention). There is some evidence that children with ASC may achieve higher scores on the LIPS-R than on other measures of general ability (Grounhuis & Mulick, 2013). The complexity of administration and abandonment of the frame and block presentation make it less usable with individuals with more severe intellectual disabilities.

The Leiter-3 has been developed for use with individuals from age 3 to 75 and is described as measuring cognitive, attentional and neuropsychological abilities. It has been designed for use with individuals with cognitive delay, those who do not have English as their first language, those with ASC or have speech or hearing impairments. It is normed on a sample of 16,000 ‘typical individuals’ and was published in 2013. This version has 10 subtests (compared to the LIPS-R’s 20) and has a block and frame format. It also includes a social/emotional Examiner rating scale. It provides global IQ score, subtest and composite scores.

Raven’s Matrices

Raven’s progressive matrices are a series of tests of non-verbal reasoning and again can be useful in assessing an individual with limited verbal communication. The test requires only one basic instruction and responses can be given verbally or by pointing. There are three forms of the test, each getting progressively more difficult: Coloured Matrices, Standard Matrices and Advanced Matrices. The Coloured Matrices may be the most useful test for individuals with intellectual disabilities. The scores from this test can be converted to scores on the Standard Matrices.

The Mill Hill Vocabulary Scale (MHV) was developed for use in conjunction with the Raven’s Matrices to give an indication of verbal functioning. Where this is not available this purpose may also be achieved by using the British Picture Vocabulary Scale (BPVS).
British Picture Vocabulary Scale

There are now three versions of this scale. The original version with line drawings has been found to be more useable with individuals with intellectual disabilities. The third version has an age range 1 to 16 years and gives an indication of receptive vocabulary. The colour pictures have black outlines to make them usable with individuals who may be colour blind.

Repeatable Battery for the Assessment of Neuropsychological Status (RBANS) Update (2012).

The RBANS provides a brief, individually administered battery which assesses the following domains:
- Immediate Memory;
- Visuospatial/Constructional;
- Language;
- Attention Delayed Memory.

There are four parallel forms, with forms A and B adapted for use in the UK. The RBANS may be used as a neuropsychological ‘screen battery’ when lengthier standardization assessments are either impractical or inappropriate. It can also be used for repeat evaluations when an alternate form is needed to control for content practice effects.

It is likely to be useable with individuals with significant intellectual disabilities.

Measures of learning

The following measures are not formal measures of general cognitive ability but may be helpful in answering clinical questions for individuals who are unable to complete any of the above measures.

The Assessment of Basic Learning Abilities (ABLA)

The ABLA (Kerr & Meyerson, 1977) was developed for use with children or adults with profound, severe and moderate intellectual disabilities to provide information for teachers and rehabilitation workers to help match task difficulty with learning ability. It involves attempting to teach six hierarchically ordered tasks using standard prompting and reinforcement procedures.

Vause et al. (2007) reviewed the data supporting this assessment and conclude that it has high test-retest and inter-rater reliability and is highly predictive of the difficulty an individual will have learning educational, prevocational and vocational tasks. It is helpful in identifying skills deficits and in minimising inappropriate behaviour by helping identify the most appropriate demand levels. The test is considered useful with individuals with profound and severe intellectual disabilities of any age and moderate and mild intellectual disabilities up to their early teens.

This test may provide clinically useful information for individuals unable to complete more intellectually demanding tests but will not give information about specific cognitive deficits. Instructions for creating the test materials and administration are given in Vause et al. (2007).
Teacch Transition Assessment Profile – TTAP

The TTAP (Mesibov et al., 2007) is an updated version of the AAPEP (Adolescent & Adult Psycho-Educational Profile). It is aimed at individuals with severe to mild intellectual disabilities and ASC. It looks at functioning across domains (home and work/education) and also explores abilities through a range of test items. It has verbal and non-verbal instructions, flexible order of presentation and flexible time limits. The scoring system allows comparisons across functional areas and environments.

This test may provide clinically useful information for individuals with ASC who are unable to complete more demanding tests.

Tests of memory

There are a number of standardised batteries of memory tests available including the Wechsler Memory Scales – Third and Fourth Edition, the Rivermead Behavioural Memory Test (RBMT, RBMT-E (extended version), RBMT-II and RBMT-3) and the Doors and People Battery. There is also a non-standardised memory battery developed for use with individuals with intellectual disabilities; the Cambridge executive functioning assessment: memory tests – CEFA-M (Ball et al., 2008; Willner et al., 2010).

There are also a large number of stand-alone tests of different elements of memory such as the Rey Complex Figure Test.

Standardised test batteries

The Wechsler Memory Scales (WMS-III/WMS-IV) are only useful for more able individuals as they involve quite complex instructions and many of the subtests are verbal in nature. Where it can be used interpretation is helped by the data provided comparing scores on the test to those predicted from an individual's score from the WAIS-III/WAIS-IV.

There is no data on the effects of retesting using the WMS-IV. See the manual for recommendations for administration where re-testing is likely to be needed.

The Rivermead Behavioural Memory Test is easier and the recent edition (RBMT-3) has adopted the same scoring criteria as the Wechsler scales which makes comparison across different tests easier. It is also the only standardised test that assesses prospective memory. It has two versions, allowing for retesting (see manual for recommended order of administration). The manual includes advice on adaptation for individuals with motor impairments.

The Doors and People battery may also be useful as the instructions are simpler than the WMS-III/WMS-IV and many of the subtests use visual material in the administration. It assesses visual recognition, visual recall, verbal recognition and verbal recall.

The Autobiographical Memory Interview (Kopelman & Wilson, 1990) was developed to investigate retrograde amnesia in adults. It tests the individual’s recall of facts from their own past life and also recall of specific incidents in their earlier life. This is likely only to be useable with individuals with mild intellectual disabilities. It is also suggested that the information provided by the individual should be validated by interviewing a carer, family member or member of staff who has known them for a long time.
Non-standardised test batteries

The Cambridge Executive Functioning Assessment – Memory (CEFA-M) is part of a wider assessment battery originally compiled to explore the changes in executive functioning in individuals with Down’s syndrome (Ball et al., 2008) and later extended for use with other individuals with mild and moderate intellectual disabilities (Willner et al., 2010). It comprises tests of: object memory; prospective memory; memory for sentences; immediate memory; delayed recognition; and delayed recall. These tests are derived from a number of sources. There are standardised instructions (Ball et al., 2008) but no norms.

The battery has a low floor. However, it also has a low ceiling (70 per cent of Willner et al.’s sample scored the maximum on at least one test). Hence the CEFA-M may be useful for individuals who are not able to complete any of the standardised memory tests.

The Neurological Assessment for individuals with Intellectual Disabilities (NAID; Crayton et al., 1998) is described more fully in BPS (2015a). This battery includes tests of object memory, picture memory and memory for sentences. These items are quick and easy to administer. They have a low floor and low ceiling. Like the CEFA-M they may be useful with individuals who are unable to complete standardised memory tests.

Memory for sentence tests are particularly helpful as they suggest the maximum length of sentence that should be used when communicating with the individual.

Tests of executive functioning

There are a number of standardised assessments of executive functioning available including:

- The Behavioural Assessment of Dysexecutive Syndrome (BADS; Wilson et al., 1996);
- The children’s version of the BADS (BADS-C; Emslie et al., 2003);
- The Delis-Kaplan Executive Function System (D-KEFS; Delis, Kaplan & Kramer, 2001);
- The Test of Everyday Attention (TEA; Robertson et al., 1994);
- The test of Everyday Attention for Children (TEA-Ch; Manly et al., 1998);
- The Wisconsin Card Sorting Test (WCST; Grant et al.);
- The Trail Making Test (1944);
- The Stroop (Stroop, 1935);
- Tests of verbal fluency;
- The Hayling and Brixton (Burgess & Shallice, 1997).

Many of the tests developed to explore executive functioning in the general population are too complex or too dependent on verbal skills to be used with individuals with intellectual disabilities (Masson et al., 2010). In addition, interpretation is hampered by the lack of norms for this population. However, this is a developing area and a number of tests of executive functioning have been adapted for individuals with intellectual disabilities. While few of these measures have had their psychometric properties tested or give norms for this population they offer a basis for assessment provided the results are interpreted with due caution. They can be a rich source of qualitative information.
Standardised tests

The BADS is a battery of tests designed to sample a range of executive functions. The subtests are based on real-life activities: creating and implementing a strategy to find a lost key, solving an unfamiliar problem, navigating unfamiliar terrain using a map, using one’s existing knowledge to estimate time periods of particular tasks, and organising and completing a collection of small tasks within a time limit.

The BADS has complex instructions, some complex tasks and makes demands on working memory. Some instructions are given in writing, to reduce the load on working memory. However, this will only benefit individuals with good literacy skills. Some subtests may be useable with the most able individuals.

Although the BADS purports to be a comprehensive assessment of executive functioning it does not adequately assess some skills, for example verbal set shifting and inhibition.

The BADS-C has slightly less complex instructions and less complex tasks than the BADS. By definition it is normed for use with children. The usefulness of the BADS-C with individuals with intellectual disabilities has been explored (Willner et al., 2010). Despite this being a less complex test than the BADS there was still a significant floor effect with many participants scoring zero on three of the six subtests. Like the BADS it does not assess verbal set shifting and inhibition.

The D-KEFS is a battery of nine tests designed to be used flexibly to sample the full range of executive functions. Many of the tests are improved versions of older tests and provide better standardization and a larger representative norm group. However, many of the tests are too complex for individuals with intellectual disabilities. Individuals with intellectual disabilities were excluded from the normative samples.

The TEA measures three aspects of attention – selective attention, sustained attention, and attentional switching. It comprises of eight subtests based on real-life scenarios, three parallel versions are provided. The complicated verbal instructions and the degree of imagination required (e.g. imagining you are on a holiday in Philadelphia) suggests that it would be difficult to administer and meaningfully interpret for people with intellectual disabilities.

The TEA-Ch comprises nine subtests which measure children’s abilities to selectively attend, sustain their attention, divide their attention between two tasks, switch attention between tasks and inhibit verbal and motor responses. It is designed for use with ages 6 to 16 years. This is simpler and more visual than the TEA.

The Trail Making Test is a test of speed of attention, sequencing, mental flexibility, visual search and motor function. In Part A of the test the individual has to connect by drawing a pencil line, the numbers 1 to 25 randomly arranged on a page. In Part B of the test the individual has to connect randomly arranged numbers and letters, in an alternating sequence, keeping both the numbers and letters in order. The test is fully explained and normative data is supplied in Spreen and Strauss (2006). This test is also included in the D-KEFS. Caution: If administering this test to an individual with intellectual disabilities ensure that they know both numbers and letters first.
The Coloured Trails is an alternative version of the Trail Making Test. It still requires that the individual can sequence numbers 1-25 but replaces letters with colours pink and yellow and the use of symbols. This may be more accessible for individuals with intellectual disabilities.

*Caution:* Check that the individual is not colour blind and that they know the colours used in the test.

Stroop tests measures the ease with which an individual can shift perceptual set to conform to changing demands and suppress a habitual response in preference to an unusual one. A number of versions of the Stroop have been developed, and these are described in Spreen and Strauss (2006). Again these are too difficult for all but the most able individuals with intellectual disabilities.

The WCST is a measure of set shifting and, in general, would be thought to be too complex for individuals with intellectual disabilities.

**Tests of Verbal Fluency**

In tests of Verbal Fluency the individual produces as many words belonging to the same category (e.g. same initial letter or same semantic category) as they can within a timed period. Letter fluency is most frequently assessed using the letters F, A and S. Instructions for administration are given in Spreen and Strauss (2006), Verbal fluency also forms one of the D-KEFS tests.

Verbal fluency tasks based on initial letters are too complex for all but the most able individuals with intellectual disabilities. Those based on categories may be more accessible.

**Hayling & Brixton Tests**

The Hayling comprises two sets of 15 incomplete sentences which are read aloud to the individual who is then required to complete the sentence complying with the given rule. It gives measures of simple response initiation speed, the ability to suppress and thinking time. Some of the sentences are complex and may not be understood by individuals with intellectual disabilities. However the test may be useful with more able individuals.

The Brixton spatial anticipation task measures the ability to detect rules in a sequence of stimuli. However it is too complex for the majority of individuals with intellectual disabilities.

**Non-Standardised tests**

**Test Batteries**

*BADS-Downward extension*

The BADS has recently been adapted to provide a simpler, more accessible version and some limited normative data is available (Dodd & Webb, 2014). It comprises set shifting card task, the action program task, key search, supermarket map and four element tasks. The supermarket map replaces the zoo map task. The four elements task is a simplified
version of the task presented in the BADS-C. Temporal estimates has been removed from the battery as it proved impossible to develop a meaningful version of this task that was accessible to individuals with intellectual disabilities. The instructions have been simplified and are supported by pictures and short sentences to reduce the load on working memory. It requires access to the full BADS kit and the use of a BADS record form.

The BADS-downward extension covers a wide range of abilities. Comparison with the CEFA-EF (Webb et al. in preparation) shows the BADS-downward extension to have both a lower floor and higher ceiling. It also covers a wider range of executive functions and is less reliant on working memory.

The tests provide useful information about how an individual plans, problem solves and approaches novel tasks.

*Cambridge Executive Functioning Assessment – Executive Functions (CEFA-EF)*

Ball et al. (2008) compiled a battery of tests to examine a number of different aspects of EF. Criteria for selecting tests included: complying with Pennington and Ozonoff’s (1996) recommendations for areas of executive functioning that are available for neuropsychological assessment, having already been used with people with intellectual disabilities, ease of availability, brevity and the use of simple verbal instructions. The CEFA-EF comprises: verbal fluency (animals), simplified stroop (cats and dogs), spatial reversal (coin hidden below boxes behind a screen), Weigl card sorting, simplified Tower of London and scrambled boxes (finding coins hidden under boxes in view that are then moved around).

The CEFA-EF tests have been used with individuals with Down’s syndrome (Ball et al., 2008) and other intellectual disabilities (Willner, 2010). With the exception of spatial reversal these tests have a low floor (42 per cent of Willner’s sample score the minimum). The ceiling is also acceptable for all but the cats and dogs task and the Weigl tasks (25 per cent and 32 per cent maximum scores respectively).

Administration instructions for all CEFA-EF tests are given in Ball et al. (2008). Despite modification to the instructions there is some evidence that CEFA-EF tasks make significant requirements of working memory. Hence it should be interpreted with caution in individuals identified to have deficits in working memory.

*The Measure of Everyday Planning (MEP)*

Webb et al. (2014) developed the MEP as a flexible tool to help identify the issues underlying difficulties that adults with intellectual disabilities may have with independently initiating, planning and carrying out everyday activities. It explores subtle factors that can impair the performance of individuals who, superficially, appear to have the ability to carry out tasks but, in reality, struggle with them. It is also intended to be used as part of wider assessments for example the ability of individuals with learning disability to live independently or to parent children. It looks at initiation, planning/sequencing, memory and attention/concentration.
It can be administered by three methods:

- Interview with the individual;
- Interview with an informant who knows the individual well;
- Observation of the task (more practical for everyday tasks that can be completed within a short period of time, for example, making a hot drink).

Combinations of tasks and methods of assessment can be used flexibly to explore issues such as perceived vs actual performance and to look at reliability of results.

This test is currently being piloted with individuals with intellectual disabilities (Dodd & Webb, 2014).

**Single tests**

**The Weigl Colour-Form Sort Test (WC-FS; Goldstein & Scheerer, 1953)**

The WC-FS is a simplified version of the Wisconsin Card Sort Test and is a measure of set shifting. It assesses the ability to categorize across two dimensions, involving ignoring a salient dimension (colour) to categorise by a less salient dimension (form). Instructions for administration and scoring are given in Byrne, Bucks and Cuerden (1998). Test material consisted of nine tokens; three circles, three triangles, and three squares, each shape coloured blue, red, or yellow on one side and white on the reverse. The participant is asked to sort the tokens so that they go together and then asked to sort them in a different way. The scoring system takes into account the established finding that sorting by form is more difficult than sorting by colour for people with organic impairment, and therefore awards a higher score to those who sort by form without prompting. Ball et al. (2008, p.7) give a system of increasingly directive prompts to use with individuals who do not change sorting dimension.

*Caution:* When administering this test it is essential that you ensure the individual is not colour blind.

**Simplified Stroop tests**

**Simplified Stroop** There is an simplified version of the Stroop available. In this version there are fewer words and the font is much larger. As in the original version, there are two parts to the test. In Part A of the test the individual has to read the words out loud. In the second part of the test the individual is asked to name the colour of the ink each word is written in. The time taken to complete each part is recorded and the test is scored as a simple pass/fail. Individuals with executive problems may struggle with the second part, need reminders to stay on task or perform very slowly.

**The Day/Night Stroop** (Gerstadt, Hong & Diamond, 1994) was developed for use with children and does not require reading skills. It randomly presents pictures of the sun and moon, representing day and night. The child first names the pictures and then is required to say ‘night’ for the sun picture and ‘day’ for the moon picture. While this is a simpler form it does not appear to have been used with individuals with intellectual disabilities and has the disadvantage that the response required is not the obvious one suggested by the picture.
The Cats and Dogs Stroop (Ball et al., 2008) comprises a significantly modified version of the Day/Night Stroop. Pictures of the sun and moon are replaced with pictures of cats and dogs on the basis that these evoke a single obvious response, that is, when shown a picture of a cat it is highly unlikely that an individual would respond by saying anything other than cat. This was used successfully with individuals with Down’s syndrome (Ball et al., 2008) and other individuals with intellectual disabilities (Willner et al., 2010). It comprises one of the tests that make up the CEFA-EF. Instructions are given in Ball et al. (2008, p.7).

Simplified Tower of London tasks

The Tower of London (TOL) paradigm is based on the requirement to move balls on a number of pegs in order to match a goal arrangement within a set number of moves and in accordance with certain rules. A version forms part of the D-KEFS tests. It explores planning and problem solving skills.

Several researchers have adapted and simplified the TOL task to make it more accessible to individuals with intellectual disabilities (Ball et al., 2008; Rowe et al., 2006). The adaptations and changes to the scoring system vary and hence care should be taken when comparing results. This applies both for repeated assessments of one individual, that is, the clinician will need to check that the method used and the scoring criteria were similar over repeated testing and when comparing with results presented in the literature, that is, ensuring that the research study used the same method as the assessment of the individual. The version of the TOL used by Ball et al. (2008) comprises one of the tests in the CEFA-EF (Willner et al., 2010). To make future comparison possible the method used and scoring criteria should be clearly referenced in the report.

Simplified verbal fluency

The semantic category of animal names is considered easier for individuals with intellectual disabilities than generation of words from an abstract category, such as common initial letter, and is less dependent on literacy skills (Rowe et al., 2006). Harrison et al. (2000) report that the animal names version correlates well with the initial letter (‘FAS’) version. The individual is asked to say as many animal names as they can within one minute. The score is the total number of unique animal names generated in 60 seconds. Ball et al. (2008, p.7) give suggested prompts for individuals who seek clarification or become stuck. This test also forms part of the CEFA-EF battery.

Test batteries for Alzheimer’s disease/dementia

See BPS (2015a), Dementia and people with intellectual disabilities: Guidance on the assessment, diagnosis, interventions and support of people with intellectual disabilities who develop dementia.
This document aims to provide guidance to promote ethical and effective neuropsychological assessment of individuals with intellectual disabilities. The key recommendations are given below:

1. To effectively use neuropsychological tests in their clinical practice with individuals with intellectual disabilities, clinical and other qualified psychologists should:
   - Review their skills in the selection, administration and interpretation of tests;
   - Where appropriate, seek opportunities to develop or update these skills;
   - Seek supervision from clinical psychologists or neuropsychologists with extensive experience in the use of neuropsychological tests with individuals with intellectual disabilities.

2. Assessment of acquired neurological insult/injury in individuals with pre-existing intellectual disabilities should be undertaken in collaboration with or under the supervision of a neuropsychologist. Consultation with a neuropsychologist should also be considered where the individual has a history of head injury, illness resulting in brain damage or has epilepsy.

3. A neuropsychological assessment must be part of a wider, planned assessment process. There should be a clear rationale, with assessment undertaken to answer specific questions about an individual’s cognitive functioning.

4. The process used to seek consent to neuropsychological assessment and testing must comply with the Mental Capacity Act (2005).

5. Thorough information gathering is essential to inform the selection, administration and interpretation of tests. This will also inform the choice of and improve the effectiveness of remedial strategies.

6. Test selection must take into account the questions to be answered, the characteristics of the individual, the characteristics of the tests available and the experience of the assessor.

7. The testing situations should be carefully planned to maximise the chances of the individual performing at their best and to promote the safety of all involved. The wellbeing of the individual and the safety of all involved must always take priority over the test requirements.

8. Qualitative information can be as, if not more, important than test scores in answering questions. Collecting this information is an essential part of the testing process.

9. Care must always be taken that tests are correctly scored and that only valid scores and composite scores are reported. Presentation of results in reports should comply with BPS (2015b).

10. Interpretation of the results of testing should be sophisticated: taking into account all the information gathered, research findings and theoretical understanding of cognitive processes.

11. Neuropsychological assessment should lead to recommendations that are integrated into the individual’s care plans/positive behaviour support plan.

12. Dissemination of the results of a neuropsychological assessment is essential and will usually go beyond a clinical report to include accessible reports and education.
References


www.nice.org.uk/guidance/cg137/chapter/guidance.


Appendices

Appendix 1: Template for seeking consent to cognitive assessment

<table>
<thead>
<tr>
<th>Tick</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Introduce yourself to the individual.</td>
<td></td>
</tr>
<tr>
<td>Explain who has asked you to see them.</td>
<td></td>
</tr>
<tr>
<td><strong>Explain that they have asked for you to carry out a cognitive assessment and the reason for the assessment</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Reason(s) for the assessment:</strong></td>
<td></td>
</tr>
<tr>
<td>Seeing if you have learning/intellectual disabilities.</td>
<td></td>
</tr>
<tr>
<td>Finding out what you’re good at and need help with.</td>
<td></td>
</tr>
<tr>
<td>To see if the way you think, the things you are good at and the things you find difficult are part of the reason you have been behaving in ways others find difficult (challenging behaviour) or get you in to trouble (offending behaviour)</td>
<td></td>
</tr>
<tr>
<td>To see how the way you think, the things you are good at and the things you find difficult affect your parenting</td>
<td></td>
</tr>
<tr>
<td>To see whether you can fully understand whether you can decide to…</td>
<td></td>
</tr>
<tr>
<td>To help us understand specific difficulties that you are having, and to look at how you approach tasks.</td>
<td></td>
</tr>
<tr>
<td>Finding out if there have been any changes in your thinking, for example, after an injury, or if dementia is suspected</td>
<td></td>
</tr>
<tr>
<td><strong>Other:</strong></td>
<td></td>
</tr>
<tr>
<td>Tell them that you will talk with them about the assessment, what it involves and the potential benefits and risks of the assessment. Tell them that they can then choose whether they want to do the tests.</td>
<td></td>
</tr>
<tr>
<td>Say you need to think whether you want to have the test. You can do the test if you want to. You can refuse to have it if you don’t want it.</td>
<td></td>
</tr>
<tr>
<td>Explore with them the potential benefits and risks of carrying out the assessment</td>
<td></td>
</tr>
<tr>
<td><strong>Potential benefits and risks:</strong></td>
<td></td>
</tr>
<tr>
<td>You will know more about your strengths and weaknesses.</td>
<td></td>
</tr>
<tr>
<td>The results will give answers to the referral question.</td>
<td></td>
</tr>
</tbody>
</table>

*Continued*
<table>
<thead>
<tr>
<th>Tick</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>We can advise your GP/Family/Home/Day centre (delete as appropriate) how they can use this information to help you.</td>
<td></td>
</tr>
<tr>
<td>You need to be aware that if your scores tell us you don’t have learning disabilities, then you might not get any services from our team/other learning disability services.</td>
<td></td>
</tr>
<tr>
<td>You might find the tests enjoyable and interesting or you might find them hard work and might get tired or upset</td>
<td></td>
</tr>
<tr>
<td><strong>Other:</strong></td>
<td></td>
</tr>
<tr>
<td>Ask if they have had a copy of the Cognitive tests accessible leaflet – if not give a copy if appropriate and go through it</td>
<td></td>
</tr>
<tr>
<td><strong>Explain what a cognitive assessment is:</strong> a cognitive assessment looks at thinking skills such as remembering, solving problems, number skills and planning. There are questions, word games and puzzles. It tells us how you are doing compared to others.</td>
<td></td>
</tr>
<tr>
<td><strong>Explain the tests you are planning to do:</strong></td>
<td></td>
</tr>
<tr>
<td>IQ</td>
<td></td>
</tr>
<tr>
<td>Memory</td>
<td></td>
</tr>
<tr>
<td>Planning and organising</td>
<td></td>
</tr>
<tr>
<td>Attention</td>
<td></td>
</tr>
<tr>
<td><strong>Explain the test process:</strong></td>
<td></td>
</tr>
<tr>
<td>Cognitive tests start easier and get more difficult. Everyone gets to that stage and that’s OK.</td>
<td></td>
</tr>
<tr>
<td>I can’t tell you the right answer.</td>
<td></td>
</tr>
<tr>
<td>I might need to see you more than once to complete the test(s).</td>
<td></td>
</tr>
<tr>
<td>I won’t be able to give you the scores on the same day.</td>
<td></td>
</tr>
<tr>
<td>We will need to meet again so that we can talk about the things that you did well and the things you found more difficult.</td>
<td></td>
</tr>
<tr>
<td><strong>Explain who can be present for the assessment:</strong></td>
<td></td>
</tr>
<tr>
<td>Supporter for the individual</td>
<td></td>
</tr>
<tr>
<td>Supporter for the assessor (i.e. for safety)</td>
<td></td>
</tr>
<tr>
<td>Observer for the observers development</td>
<td></td>
</tr>
<tr>
<td><strong>Explain the reporting process:</strong></td>
<td></td>
</tr>
<tr>
<td>I will give you a copy of the report for you to keep. You can have the full report or a copy that you can understand more easily, or both.</td>
<td></td>
</tr>
<tr>
<td>I will send a copy of my report to…</td>
<td></td>
</tr>
<tr>
<td>Is there anyone else you would like to have a copy of the report?</td>
<td></td>
</tr>
<tr>
<td>Explain that the report will be kept on file/their electronic record.</td>
<td></td>
</tr>
<tr>
<td>Ask if they have any other questions – answer these.</td>
<td></td>
</tr>
</tbody>
</table>

*Continued*
Appendix 1: *Continued*

<table>
<thead>
<tr>
<th>Tick</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Check that they have understood the above points, for example, ask them to tell you what they understand about the assessment.</td>
<td></td>
</tr>
<tr>
<td>If they appear to have understood the explanations, ask if they want to take part in the assessment.</td>
<td></td>
</tr>
<tr>
<td>Record their decision:</td>
<td></td>
</tr>
<tr>
<td>If they do not appear to have understood the explanations, does this raise concerns that they may lack the capacity to make this decision?</td>
<td></td>
</tr>
<tr>
<td>If so carry out a two part capacity assessment</td>
<td></td>
</tr>
<tr>
<td>Record the outcome of the capacity assessment:</td>
<td></td>
</tr>
<tr>
<td>If lacking capacity to make this decision record the process carried out to explore Best Interest.</td>
<td></td>
</tr>
</tbody>
</table>
Appendix 2: Accessible information leaflet about cognitive assessment

Cognitive Assessments

An Easy Read leaflet for People with Learning Disabilities
# Cognitive Assessments

## What is a cognitive assessment?

<table>
<thead>
<tr>
<th>A cognitive assessment looks at:</th>
<th>What you are good at and what you find difficult.</th>
</tr>
</thead>
</table>
| A cognitive assessment measures types of thinking. | Types of thinking include:
<p>| Memory |
| Problem solving |
| Attention |
| Planning &amp; organising |</p>
<table>
<thead>
<tr>
<th>What happens in a cognitive assessment?</th>
</tr>
</thead>
<tbody>
<tr>
<td>You will complete the cognitive assessment with a psychologist. The psychologist might be a man or a woman. They might be young or old.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>?</th>
<th>The psychologist will ask you some questions.</th>
</tr>
</thead>
<tbody>
<tr>
<td>The psychologist will ask you to do some games and puzzles.</td>
<td></td>
</tr>
<tr>
<td>Meeting 1</td>
<td>The first meeting will be for about an hour.</td>
</tr>
<tr>
<td>1 Hour</td>
<td></td>
</tr>
<tr>
<td>1</td>
<td>2 or 3</td>
</tr>
<tr>
<td>+ +</td>
<td>There may need to be two or three meetings.</td>
</tr>
</tbody>
</table>
### What happens in a cognitive assessment?

<table>
<thead>
<tr>
<th>Thumb up then thumbs down</th>
<th>Most assessments start off easy and get harder. Everyone finds them difficult at the end.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Person looking tired</td>
<td>If you get tired in the assessment you can ask for a short break.</td>
</tr>
<tr>
<td>STOP</td>
<td>If you want to stop the assessment you can say ‘Stop’.</td>
</tr>
</tbody>
</table>
**What to bring to the assessment:**

<table>
<thead>
<tr>
<th>Item</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Glasses</td>
<td></td>
</tr>
<tr>
<td>Hearing aid with battery</td>
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<td>You can choose to have a family member or a member of staff come in with you.</td>
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<tr>
<td>They can watch the assessment.</td>
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<tr>
<td>They will not help you with any answers.</td>
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</tbody>
</table>
The psychologist may need to have someone come in with you. They will make sure you are both safe.

After the assessment, the psychologist will write a report about the results.

You can meet again to talk about the report.
The report will be sent to the person who asked the psychologist to see you.

You can ask to have a copy of the report with pictures.

You can ask for the report to be sent to your family or people who support you.
Appendix 3: Suggested report headings and issues to consider

Name: .............................................................................................................................................
Address: ..........................................................................................................................................
........................................................................................................................................................
D.O.B: ............................................................... NHS number: ...................................................
Referred by: ...................................................... Date of report: ..................................................

Reason for referral

Background information
This section should present and structure information that is relevant to interpretation for the individual. The use of sub-headings is recommended. Possible sections might include:

1. Educational and Occupational History

Schooling
Previous schooling, educational level reached, college courses attended/passed.

Employment
Any employment (including voluntary work) and whether successful or not.

Current daily activities
Details of current day activities.

2. Medical History

Intellectual disability
Presence/presentation of any syndrome associated with intellectual disabilities (e.g. Down’s syndrome, Fragile-X).
Current description used for the intellectual disability e.g. significant, mild, moderate, severe, profound).
Developmental history (e.g. delayed milestones)

Pervasive developmental disorder
Presence/presentation of any pervasive developmental disorder (e.g. Autism Spectrum Disorder).

Physical health
History of significant illnesses (e.g. meningitis, measles with complications), accidents or injuries (particularly head injuries).

Current health
Including: the presentation of any chronic health problems (e.g. diabetes, epilepsy) and how well controlled these are, levels of pain and any recent changes in health.
Physical and sensory disabilities/any aids used (e.g. glasses, hearing aid).

Mental health
History of mental health problems, current mental health and any recent changes.
Use/misuse of drugs/alcohol, history and current pattern.
Recent life events, for example, moving home, bereavement, breakdown in relationships.

Medication
Generic name of medication and dose, why prescribed, any recent medication changes, individual’s compliance with medication regimen.
Medication taking at the time of the assessment.

3. Social History

Placement
History of family and hospital and residential placements, pattern of and reason for any placement breakdown.
Current placement and frequency and duration of current support, whether individual appears to be coping or not.

Social network
Current pattern of relationships and access to informal support.

Behaviours that challenge
Description and history of behaviours that challenge, for example, physical aggression.

4. Previous Testing

Details of any previous testing: date, age of person at time, who by, test administered and results.
Where previous assessments used different tests, add the relevant statement regarding the comparison between the tests (see Appendix 4 for comparisons of Wechsler Tests).

Consent
Record that informed consent was given and the process by which this was obtained. If assessment was observed, also record process of seeking consent for observation.

Where the individual lacks capacity include summary of the two part capacity assessment, what was done to try to facilitate understanding and how the best interest decision was reached.

Assessment
Give details of the ways information was gathered and the testing carried out.

Include sources of background information e.g. information was collated from case file, interview(s) with informants (name, role/relationship, date), reports (author, role, date of report).

Give details of any pre-assessment/rapport building sessions with the individual.

Test(s) administered
List the tests administered giving the full title of the test and any abbreviation used in the report, for example, The Wechsler Adult Intelligence Scale – Fourth Edition (WAIS-IV).
(The nature and purpose of these tests is explained in the results section. With multiple tests it is most helpful for the reader to have an explanation of the test together with the results of that test.)

Give details of the administration including: where, when (dates), over how many sessions.

Note the presence of any other people in the assessment session (name, role, reason for presence).
Note any deviations from the standard administration of the tests and the reasons for this.

Note any environmental factors that might have impacted on the results, for example, noise, interruptions.

**Behaviour and presentation during the assessment**

Behaviour and motivation during the test procedure.

Were breaks necessary and why?

Distractibility within the environment.

Was the person very anxious/inattentive/restless?

Were they excessively sleepy?

Did they persevere on tests items they found hard?

Did they appear motivated to perform to the best of their abilities?

Did they appear to enjoy/dislike particular subtests?

Overall do you think the results are a valid reflection of their current ability level?

**Results of current assessment**

Test results should be grouped by the purpose of the test, for example:

- General intellectual ability;
- Tests of learning;
- Tests of memory;
- Tests of executive functioning.

The results of each test should begin with a brief description of the test and what areas of functioning it measures, for example:

The WAIS-IV is the latest revision of the Wechsler Adult Intelligence Scale. It is a battery of verbal and performance subtests which enables an assessment of both Full Scale IQ and a range of index measures, reflecting particular strengths and weaknesses. The WAIS-IV is made up of four IQ indices; Verbal Comprehension (VC), Working Memory (WM), Perceptual Organisation (PO) and Processing Speed (PS). Only if an individual scores similarly on the four indices can they be combined together to give Full Scale IQ. Where there are significant differences between index scores it may be appropriate to calculate other indices e.g. General Ability (GA) and Cognitive Processing (CP).

The results are then presented use subheadings to break up the text, for example:

Verbal Comprehension, Perceptual Organisation

The results presented will depend upon the findings in your analysis. For standardised tests only present results which the analysis has shown to be meaningful (i.e. meet the Lichtenberger & Kauman, 2009, criteria for interpretability).

Comments should be made regarding significant differences. Where no significant differences exist there is no need to comment on these (in measurement theory differences that do not meet the significant value are due to chance variation and do not represent a ‘real’ difference in abilities).

As well as commenting on any significant differences between subtest scores, it may be beneficial to comment if the individual appeared to enjoy or alternatively dislike particular subtests.

Unless there is a powerful reason (e.g. request by a court) do not present IQ figures in the report. Rather present the range in which the score is likely to lie, giving the confidence level used (e.g. 54 to 61 95 per cent confidence level). Present results in numbers in the Appendix for psychologists only.
For non-standardised tests give information about the normative data available, the limitations on interpretation and qualitative information on performance. For example:

**Executive abilities**
A number of tests of executive ability were administered. It should be noted that for a number of these tests there is little normative data available for individuals with an intellectual disabilities, and so the results should be interpreted with a degree of caution. However how an individual performs on these tests can provide relevant qualitative information in addition to the actual scores on the individual tests.

(a) **Behavioural Assessment of Dysexecutive Syndrome**

*Rule Shift Card Test*
This test assesses an individual's ability to respond to a rule and shift from one rule to another. On this test XXXXX was able to comply with the first rule, but found it difficult to shift, and perseverated to using the first rule, suggesting difficulties with flexibility of thinking.

*Action Programme Test*
This is a test of non-verbal problem solving, for which the examiner can provide set prompts to help the individual solve the task. XXXXX was unable to solve the problem without a number of these prompts. He also exhibited perseveration in that, despite having first used an unsuccessful strategy, he continued to return to this a number of times in an attempt to complete the task.

It may also be helpful to summarise the results of assessments of particular areas of functioning, for example, memory, executive functioning, attention in relation to a helpful model. For example:

**Summary of executive tests**
There is no universal agreement over the exact taxonomy of executive functioning and the models in the literature do have recognized difficulties (e.g. overlap between areas defined as distinct). There is even less research on executive functioning of adults with a learning disability. However, Lezak (1995) splits executive functioning into four areas of volition, purposive action, planning and executive performance and the results of the above assessment have been matched to this model.

*Volition (awareness of self, environment and motivational state)*
XXXXX is often reluctant to engage in activities, especially those which are novel or out of his normal routine.

*Planning (ability to form strategies to achieve an objective, conceive of alternatives and make choices)*
XXXXX reported that making decisions sometimes triggers his anger. Results of neuropsychological tests suggest that he has difficulty problem solving, generating and switching between rules. He also has difficulties with divided attention (doing two things at once).

*Executing activities (ability to purposefully engage oneself)*
There were behavioural observations of impulsivity and difficulties with estimating how long activities will take. Neuropsychological testing suggested he had difficulty switching between rules and thinking flexibly. Although XXXXX has a good knowledge of anger management strategies he finds it difficult to action these at the required times. There were also observations of perseveration on tasks and in everyday behaviour.
Self-monitoring (ability to spontaneously monitor and self-correct, including avoiding perseverative responses and careless errors)

XXXXXX has little insight into his current behaviour. He also finds it difficult to regulate his emotions and inhibit responses which can lead to aggressive behaviour. He finds it difficult to self-correct errors as he does not perceive that they have occurred.

**Discussion/Formulation**

This section should:

- Explore the reliability and validity of the results presented and comment on the extent to which they give a useful profile of the individual’s cognitive functioning. Look particularly for consistencies/inconsistencies across tests purporting to measure similar or related abilities. Consider reasons for these patterns.

- Summarise the cognitive strengths and weaknesses identified from the test results. Comment on how this pattern relates to the individual’s presentation, for example:
  - Do the results suggest they are less/more able than they appear on first contact?
  - Do the results challenge others’ perceptions of the individual as ‘lazy’ or ‘understands everything said to them’?
  - Are good verbal skills leading to over-estimation of the individual’s abilities?
  - Does the individual seem to be under-performing in everyday life compared to the test results?

- Where appropriate make comparisons with peer groups or own results from previous assessments (e.g. compare with other individuals with same syndrome).

- Explore how this pattern of cognitive strengths and weaknesses might impact on the individual’s everyday functioning, including whether or not the pattern might contribute to the issues that led to referral. Where relevant this might include:
  - Identifying changes in functioning, possibility of dementia (Alzheimer’s, frontal, etc.).
  - Identifying support needs.
  - Possible impact on decision making/capacity.
  - Possible role in behaviours that challenge/pattern of offending/risky behaviours.
  - Possible impact on areas of functioning/ability to learn new behaviours, for example, as part of parenting assessment (see BPS, 2011a).

**Conclusion**

Summarise the implications of the results in relation to the referral problem.

**Recommendations**

Recommendations should include suggestions for:

- Educating the individual and those who support them about the nature and implications of the deficit.
- Identification and implementation of remedial or compensatory strategies (see recommendations section in main document for specific suggestions).
- Identification of the implications for the individual’s support package.
Any recommendations for further assessments. Consider whether a referral onto other therapies for further assessment may be beneficial. For example referrals to:

- **Speech and Language Therapy** – if the individual’s verbal IQ is much lower than their performance IQ – if there are concerns around dysphasia.
- **Occupational Therapy** – if there are issues around dyspraxia.
- **Psychiatry** – if there are concerns as regards mental health status/presentation of individual.
- **Neurologist** – if there are concerns around epilepsy or other organic processes.

Note how the results will be shared with the individual assessed and whether a separate report was prepared for them.

Signature, name and grade of psychologist

Signature, name and grade of supervisor if appropriate

Cc list
Appendix

Name: ........................................................................... D.O.B.: ..............................................................

This results section is for inclusion in the Psychology file only and should not be sent out with the standard clinical report. It is information which can only be fully understood by a qualified psychologist. (where electronic records are used this should be uploaded in a manner that allows access only to psychologists).

**Full results**

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<tr>
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<th>Scaled Score</th>
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<tbody>
<tr>
<td><strong>Verbal Comprehension</strong></td>
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<tr>
<td>Vocabulary</td>
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<tr>
<td>Similarities</td>
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<td>Information</td>
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<tr>
<td><strong>Verbal Comprehension Index</strong></td>
<td>score (range)</td>
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<thead>
<tr>
<th><strong>Perceptual Organisation</strong></th>
<th>Scaled Score</th>
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<tbody>
<tr>
<td>Block Design</td>
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<tr>
<td>Matrix Reasoning</td>
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<tr>
<td>Visual Puzzles</td>
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<tr>
<td><strong>Perceptual Organisation Index</strong></td>
<td>score (range)</td>
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<tr>
<th><strong>Working Memory</strong></th>
<th>Scaled Score</th>
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<tr>
<td>Arithmetic</td>
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<td>Digit Span</td>
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<tr>
<td><strong>Working Memory Index</strong></td>
<td>score (range)</td>
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<tr>
<th><strong>Processing Speed</strong></th>
<th>Scaled Score</th>
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<tbody>
<tr>
<td>Digit Symbol Coding</td>
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<tr>
<td>Symbol Search</td>
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<tr>
<td><strong>Processing Speed Index</strong></td>
<td>score (range)</td>
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<thead>
<tr>
<th><strong>Optional Subtests</strong></th>
<th>Scaled Score</th>
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</thead>
<tbody>
<tr>
<td>Comprehension</td>
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<tr>
<td>Letter Number Sequencing</td>
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<td>Figure Weights</td>
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<td>Cancellation</td>
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<td>Picture Completion</td>
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<tr>
<td><strong>Optional Subtests Index</strong></td>
<td>score (range)</td>
</tr>
</tbody>
</table>

The mean of each scaled score is 10, with a standard deviation of 3.

Full Scale IQ = score (range)

OR

Global Ability Index = score (range), Cognitive Processing Index = score (range)

These ranges are at the % confidence limits.
Appendix 4: Comparison of scores from different versions of the Wechsler Adult Intelligence Scale

Comparison with results obtained on past assessments

Where past assessments have been on a previous version of the WAIS adjustment for this must be made before comparing scores. It is not possible to make simple comparisons between scores attained on different versions of the WAIS because each version is slightly different in terms of test items and the final scores attained. These changes need to be taken into account when making comparisons. See table below.

The discrepancy between IQ scores attained on different versions of the WAIS.

Comparison of mean IQ scores (240 examinees aged 16 to 88) show that WAIS-IV FSIQ score is 2.9 points lower than the WAIS-II. For a group with intellectual disability (N=25) the difference was slightly larger at 4.1. (For more detailed comparisons see Technical and Interpretive Manual, pp.75–78)

Comparison of mean IQ scores show that WAIS-III FSIQ score is 2.9 points less than the WAIS-R FSIQ (the WAIS-R is a version of the test that superseded the WAIS and preceded the WAIS-R).

Comparison of mean IQ scores show that WAIS-R FSIQ is 8 points lower than WAIS IQ.

Adding these two differences together suggests that the difference expected between a score on the WAIS and the WAIS-III would be 13.8 points. This strictly applies to a person completing both assessments in a short space of time. The impact of (X) years between testing as is the case for (person’s name) is not known.
Notes