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Psychological Society  
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Division of  
Clinical Psychology  
Faculty for People with  
Intellectual Disabilities

# Guidance on the Assessment and Diagnosis of Intellectual Disabilities in Adulthood

*A document compiled by a Working Group of the  
British Psychological Society's Division of Clinical  
Psychology, Faculty for People with Intellectual  
Disabilities*

# Membership of the Working Group

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This document has been prepared by the Faculty for People with Intellectual Disabilities of the Division of Clinical Psychology, the British Psychological Society.

Membership of the Working Group was as follows:

Theresa Joyce (Chair);

Ivan Bankhead;

Terry Davidson;

Susan King;

Heather Liddiard;

Paul Willner.

## Acknowledgements

Grateful thanks are extended to all those who commented on earlier drafts of the document, and all those who attended the workshops as part of the consultation process.

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**Tel: 0116 252 9523; Email: P4P@bps.org.uk**

For all other enquires please contact the Society on:

**Tel: 0116 254 9568; Email: mail@bps.org.uk**

Printed and published by the British Psychological Society.

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The British Psychological Society

St Andrews House, 48 Princess Road East, Leicester LE1 7DR, UK.

Tel: 0116 254 9568 Facsimile: 0116 247 0787

Email: mail@bps.org.uk Website: www.bps.org.uk

Incorporated by Royal Charter Registered Charity No 229642

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## Executive Summary

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This document has been produced as guidance for clinical psychologists who are frequently asked to assess whether or not an individual has an intellectual disability. It will also be of use to commissioners, colleagues in intellectual disability services and families and individuals who are seeking clarification on this issue. The aim is to outline good practice in this area. It also considers the different contexts in which assessment of intellectual disability may be relevant, including mental health and mental capacity legislation, court proceedings, service entitlement and the family courts.

Intellectual disability is defined as significant impairment in intellectual functioning and significant impairment in adaptive behaviour (social functioning), with each of these impairments beginning prior to adulthood. In practice, a diagnosis of intellectual disability is sometimes made without reference to all three criteria and with debate over the meaning of scores on an assessment of intellectual functioning (usually known as an IQ test). This has resulted in confusion for families, service users and care providers and consequent difficulties in ensuring that individuals receive an appropriate service.

This document seeks to clarify the components of an assessment, considers the meaning of the 'scores' that are obtained and outlines the means by which psychologists reach their opinion in relation to whether or not an individual has an intellectual disability. It provides guidance on technical issues, and notes the difficulties associated with assessing intellectual functioning for people who have an intellectual disability. It also notes the relevance of psychologists using their clinical judgement in interpreting complex information.

The document recommends specific measures that should be used, and provides guidance on how findings should be presented. It also notes the importance of ensuring that assessment is undertaken by an appropriately qualified psychologist. A further recommendation is that a judgement as to whether or not an individual has an intellectual disability should only be made when all three components of the assessment are carried out by an appropriately qualified professional, who is able to justify their opinion in accordance with this guidance. This would reduce confusion for individuals, families and services.

# Introduction

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This document has been produced by the Faculty for People with Intellectual Disabilities of the Division of Clinical Psychology, the British Psychological Society (the Society), to provide updated guidance to psychologists registered with the Health and Care Professions Council (HCPC) who may be required to assess the presence of intellectual disability, or the extent of intellectual disability, in adults. Intellectual disability is the term used internationally to describe what was previously known as learning disability. The term intellectual disability will be used throughout this document.<sup>1</sup>

National and international definitions of intellectual disability generally share three key criteria. These are:

- a significant impairment of intellectual functioning;
- a significant impairment of adaptive behaviour (social functioning); with
- both impairments arising before adulthood.

These criteria are embodied in mental health and mental capacity legislation in the United Kingdom. They are also evident in the major diagnostic classification systems of the American Association on Intellectual and Developmental Disabilities (*AAIDD*), the American Psychiatric Association (*Diagnostic and Statistical Manual of Mental Disorders, DSM*) and the World Health Organisation (*International Classification of Diseases, ICD*). All three of these major diagnostic frameworks have either been recently revised (*DSM-5, AAIDD-11*) or are in the process of being revised (*ICD-11*). An increased emphasis has been placed in these revisions on the importance and appropriate assessment of adaptive behaviour, but the basic criteria incorporating limitations in intellectual and social functioning, with difficulties arising before adulthood, remain.

Recent years have seen increased pressure on services in relation to determining who is eligible to access them, and there are a number of legal frameworks where an intellectual disability can be a significant consideration in terms of actions, responses and rights. Accurate assessment is, therefore, becoming increasingly important.

Concern has been expressed about the impact of ‘labelling’ on the lives of people with learning disabilities. The Society acknowledges that a label, or diagnosis, can have a negative impact on how people with intellectual disabilities are perceived and the way they are treated. However, providing an assessment of a person's needs, and placing this in the context of their need for services, is more likely to be of benefit than a general assessment which does not signpost the way to focused support. One purpose of assessment and diagnosis is to assist in the development and provision of appropriate support and interventions aimed at benefitting the person's functioning and quality-of-life.

Concern has also been expressed about the use of ‘IQ tests’ as part of the process of determining whether or not a person has an intellectual disability. (These are tests of general intellectual functioning, so called due to their results typically being expressed in terms of an ‘intelligence quotient’, or IQ.) There has been considerable scientific debate on the accuracy of IQ testing for people with an intellectual disability, and there have been

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<sup>1</sup> A number of different terms have been used over time to describe intellectual disability. See Appendix 1 for more detail.

claims that the IQ score is of little relevance in this context. The Society's view is that the use of an IQ assessment is an essential component of the overall assessment of intellectual disability.

This is partially to ensure that United Kingdom definitions are in line with international organisations and classification systems (e.g. *DSM-5*, *ICD-10/11*, *AAIDD-11*), and also to assist in recognising and responding to the specific difficulties experienced by persons who have an intellectual disability. A significant (or severe) intellectual impairment, which arises in childhood, will have an impact on a person's social and intellectual functioning. Services that are supporting those with an intellectual disability need to recognise this in order to focus on their specific needs, which are likely to be different in certain respects from those experienced by individuals with other impairments. It is largely for this reason that the definition of intellectual disability, nationally and internationally, consists of criteria which require properly quantified impairments in intellectual and social functioning, and that these impairments began before adulthood.

The Society is also aware that carrying out a detailed assessment requires a skilled clinician and can take time. Services that are under pressure may sometimes seek to 'shortcut' this, either by using some form of screening tool or by carrying out only part of an overall assessment (which can lead to an overreliance on the IQ score, for example). The Society strongly recommends that this should not be accepted as good practice.

On the other hand, the Society recognises that some form of initial screening may be appropriate, so that a more detailed assessment is reserved only for those who definitely need it. For example, it is unlikely that an individual who has passed several GCSEs at grade C or above will have an intellectual disability. However, persons conducting screening assessments should not carry out shortened versions of either intelligence and/or adaptive behaviour assessment measures and then rely upon the results of these alone to determine whether or not an individual has an intellectual disability.

The Society recommends that IQ assessments are carried out either directly or under the supervision of appropriately qualified psychologists who are skilled in the assessment of adults who may have an intellectual disability and who are registered with the HCPC. Psychologists who undertake IQ tests should meet the criteria required by the publishers and distributors of the tests they use. The same should apply to the assessment of adaptive behaviour, since tests of adaptive behaviour are increasingly norm referenced and psychometrically based as well. In addition, the Society recommends that appropriate consent is sought in respect of any person being assessed.

The Society recognises that the decision as to whether or not an adult has an intellectual disability (or determining the extent of an individual's intellectual disability) is complex. It is not merely a matter of adding up numbers from various assessments, deciding whether or not any impairments started when the person was a child and then making a determination on that basis. As with any diagnosis, the clinician needs to make a judgement about the information gathered and how it contributes to the overall opinion. For this reason, *clinical judgement* (see below, Section 4.1) is recognised as an important component of any assessment. It is essential that any clinicians carrying out such assessments are transparent about what they have done and are able to justify their opinions.

This document is divided into five sections. Section 1 considers the various contexts in which an assessment of the presence, or extent, of an intellectual disability might be necessary. Section 2 examines the definition of intellectual disability, as well as its three essential criteria. Section 3 looks at a number of issues in relation to the assessment of intellectual disability, including the tools that should be used, how to conduct an assessment and the kinds of factors that may impact upon the results of an assessment. Section 4 considers how to interpret the findings of an assessment, with particular reference to the place of clinical judgement in that process. Section 5 considers how to report the results of an assessment of intellectual disability.

Although this document is written primarily for psychologists, the Society hopes it will also be of use to others – including other health and social care professionals, families and those involved in the legal system.

## Section 1: Contexts

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Psychologists are frequently asked to assess if an individual has an intellectual disability in the context of determining whether or not they have access to a number of legal and civil rights. These rights may be to the provision of either community care or health services. Psychologists may also be asked to assess in the context of an individual being either an alleged victim or perpetrator of a crime, of the applicability of mental health legislation, or of proceedings in the Family Court or the Court of Protection.

In deciding whether it is appropriate to undertake an assessment, psychologists need to be able to justify clearly the reason why the assessment is necessary. It needs to have a purpose; the process can be stressful and difficult for the person being assessed and it should not be undertaken without an adequate reason.

### 1.1 England and Wales

#### *Community care*

Community care legislation (e.g. the National Health Service and Community Care Act 1990, the Care Act 2014) requires local authorities to carry out an assessment of needs for services. To be eligible for this assessment, a person must appear to the local authority to be someone who has needs for care and support. Adults with intellectual disabilities are one of the groups to whom this definition applies. Decisions as to whether or not they have eligible needs should be made after the assessment.

Determination of whether or not an individual has an intellectual disability can often be the first part of this process. There can be an overreliance on the use of IQ scores in the process, as it can seem like a simple and clear-cut measure. It is, therefore, essential that psychologists give clear explanations of their rationale for stating whether or not an individual meets the criteria for an intellectual disability, that all three parts of the definition are explored and addressed, and that issues around ‘cut-off’ scores are clarified in the context of the overall clinical picture.

Psychologists should also consider whether refusal to carry out a full assessment in the circumstances could result in the individual being denied access to services to which they have a right and which they may need.

People with autistic spectrum disorder may not meet the criteria for an intellectual disability. This should not necessarily exclude them from access to a community care assessment, however, as they may still be considered ‘disabled’ within the meaning of community care legislation. This is because the definition of ‘disabled’ includes people ‘with a mental disorder of any kind’. For example, s1(2) of the Mental Health Act 1983 defines mental disorder as ‘mental illness, arrested or incomplete development of mind, psychopathic disorder and any other disorder or disability of mind’, so it is possible for individuals with autistic spectrum disorder to be considered eligible for community care services under that particular definition.

### *Access to benefits*

The benefits system is complex, but people with intellectual disabilities are entitled to certain benefits on the basis of their disability. Psychologists may be asked to assess whether or not a person has an intellectual disability in order to assist in a benefits claim. Many services refuse to do this, unless it is also in the context of eligibility for services.

### *Mental Health Act 1983 and Mental Health Act 2007*

The Mental Health Act 2007 amended s1 (2) of the Mental Health Act 1983 and states that a ‘person with intellectual disability shall not be considered by reason of that disability to be:

- (a) suffering from mental disorder for the purposes of the provisions mentioned in subsection (2B) below; or
- (b) requiring treatment in hospital from mental disorder for the purposes of sections ... unless that disability is associated with abnormally aggressive or seriously irresponsible conduct on his part’.

This means that an intellectual disability (defined as ‘a state of arrested or incomplete development of the mind which includes significant impairment of intelligence and social functioning’) does not, on its own, constitute sufficient grounds for treatment under this Act.

Psychologists may be asked to assess whether or not an individual has an intellectual disability in the context of being treated for a mental illness. If this occurs whilst they are in hospital being treated for a mental illness, then carrying out an assessment under these circumstances should be approached with extreme caution, as the validity of any results obtained is likely to be called into question.

### *Mental Capacity Act 2005*

The Mental Capacity Act 2005 provides the legal framework to allow for the making of decisions on behalf of adults who lack the capacity to make a decision (or decisions) for themselves. It seeks to provide a balance between autonomy of decision-making and protection for those who are vulnerable and lack capacity. It therefore allows for ‘unwise decisions’ for those who have capacity to make such decisions. For those who lack capacity, decisions should be made in their ‘best interests’. (The courts have noted that it is unlikely that an unwise decision would be in an individual's best interests if they lack capacity.)

The Act provides a definition of incapacity in two parts. The first part defines a person who lacks capacity as follows: ‘a person lacks capacity in relation to a matter if at the material time he is unable to make a decision for himself in relation to the matter because of an impairment of, or a disturbance in the functioning of, the mind or brain’ (s2(1)).

The associated Code of Practice states that ‘[e]xamples of an impairment or disturbance in the functioning of the mind or brain may include the following:

- conditions associated with some forms of mental illness;
- dementia;
- significant learning disabilities [intellectual disabilities];
- the long-term effects of brain damage;
- physical or medical conditions that cause confusion, drowsiness or loss of consciousness;
- delirium;
- concussion following a head injury; and
- the symptoms of alcohol or drug use’ (4.12).

An intellectual disability may, therefore, be one, but it is never the only, aspect of whether or not individuals are able to make decisions for themselves. To lack the capacity to make a specific decision, they also need to fulfil the second part of the two-stage test, which requires that they are ‘unable: (a) to understand the information relevant to the decision; (b) to retain that information; (c) to use or weigh that information as part of the process of making the decision; or (d) to communicate [the] decision (whether by talking, using sign language or any other means)’ (s3(1)).

Psychologists may be asked to assess decision-making capacity in a number of areas, including medical treatment, where to live, contact with friends and family, etc. It may be important as part of a determination to assess whether or not the person has an intellectual disability. However, it should not always be essential to carry out a full assessment of whether or not the person has an intellectual disability, as this information may be readily available in his/her records.

It is important to note that a number of decisions are excluded under the Mental Capacity Act 2005, including capacity to consent to sexual relationships, to marry, to divorce and to consent to adoption (s27(1)).

### ***Deprivation of Liberty Safeguards***

Deprivation of Liberty Safeguards form part of the Mental Capacity Act 2005. They apply only to individuals who lack capacity. Psychologists may be asked to assess whether or not an individual has an intellectual disability as part of this process. If the request is made while the person is acutely ill and in hospital, it is appropriate for the psychologist to comment on the reliability and validity of the results obtained, and perhaps suggest that an assessment should wait until the person has recovered (by which time it may no longer be necessary, of course). If the person is already resident in a care home, it is likely that a determination as to whether or not he/she has an intellectual disability will already have been made.

### ***Parenting assessment***

Referrals for assessment of intellectual disability in these circumstances should be considered very carefully, and psychologists are referred to the Society’s *Good Practice Guidance for Clinical Psychologists when Assessing Parents with Learning Disabilities* (2011). One of the issues that this document considers is the relevance of IQ as a predictor of parenting ability in adults with intellectual disabilities. It should be noted that ‘emergency’ parenting assessments are likely to be invalid (and possibly unethical).

### ***Sexual relationships and marriage***

Although these issues are specifically excluded from the Mental Capacity Act 2005, the principles of the Act are used in the determination of a person’s capacity to make decisions in these respects. Intellectual disability is not sufficient grounds to presume that an individual cannot engage in a sexual relationship or to marry. However, there is significant case law on the criteria to be used when considering these decisions, and psychologists are encouraged to keep up to date with case law relating to this (and to other decisions requiring an assessment of mental capacity).

### ***Fitness to plead***

A person who is ‘under a disability’ and who may have committed an offence may not be considered fit to plead within the criminal justice system. Determination of whether or not they are ‘under a disability’ can impact upon decisions to prosecute, whether the person can participate in the court process and sentencing/disposal decisions. The Mental Health Act 2007 defines mental disorder as ‘any disorder or disability of the mind’ and intellectual disability is considered to be a clinically recognised mental disorder. Psychologists may, therefore, be part of the process of assessment to determine whether or not an individual has an intellectual disability.

### ***Vulnerable witnesses***

People with intellectual disabilities are deemed to be vulnerable witnesses within the meaning of the Youth Justice and Criminal Evidence Act 1999. The definition of a vulnerable witness within that act includes any witness who ‘(i) suffers from mental disorder within the meaning of the Mental Health Act 1983, or (ii) otherwise has a significant impairment of intelligence and social functioning’ (s16(2)).

Vulnerable witnesses are entitled to the provision of ‘special measures’ if they are required to appear in court as a witness. Psychologists may be asked to assess whether or not they have an intellectual disability; however, any decision as to the provision of special measures is a matter for the judge to decide.

### ***Immigration/Deportation***

Psychologists may be asked to assess whether or not a person has an intellectual disability in the context of applications to remain in the United Kingdom. It is often the case that someone appealing against an immigration decision in these circumstances either does not have English as their first language or speaks no English at all. Assessment of intellectual functioning, adaptive behaviour and developmental history in these circumstances is extremely problematic, and findings may not be valid.

## **1.2 Scotland**

### ***National drivers and strategy***

The Scottish Government has published two strategy documents relating to individuals with learning disabilities in the past 14 years: *The Same as You?* (2000) and *The Keys to Life* (2013). The latter recognises that there are many different definitions of intellectual disability, and argues that those which include problems in adaptive behaviour are likely to be the most appropriate when planning statutory services and supports. Both documents describe individuals with intellectual disabilities as having a significant, lifelong condition that started before adulthood, that affected their development and which means they need help to: (i) understand information; (ii) learn skills; and (iii) cope independently. This definition is also used by the Mental Welfare Commission for Scotland, which has statutory duties to ensure that care, treatment and support are lawful and that they respect the rights and promote the welfare of individuals with mental illness, intellectual disability and related conditions.

Often psychologists in Scotland are asked to assess whether or not an individual has an intellectual disability in order to determine access to services.

## ***Legislation***

There are three key pieces of legislation relating to intellectual disability in Scotland: the Mental Health (Care and Treatment) (Scotland) Act 2003, which sets out powers and duties in relation to people with mental disorder; the Adults with Incapacity (Scotland) Act 2000, which provides means to protect and make decisions about financial affairs and welfare for persons with incapacity; and the Adult Support and Protection (Scotland) Act 2007, which makes provision for the protection of vulnerable adults from any harm including but not restricted to physical, psychological and financial harm. Psychologists are increasingly involved in adult support and protection proceedings, working alongside local authority and police colleagues.

The key definition in Scotland for legal purposes is that of ‘mental disorder’, as found in s328 of the Mental Health (Care and Treatment) (Scotland) Act 2003. It includes ‘learning disability ... however caused or manifested’. The requirement for this definition to be met in relation to the various provisions contained within the above acts is usually determined through medical evidence. However, circumstances may arise where others are required to provide information to support a diagnosis, for example, at a mental health tribunal or a court where the diagnosis of intellectual disability is borderline or contested. Psychologists are frequently asked to contribute to the assessment of capacity, particularly in situations where the medical practitioner primarily responsible views the assessment of capacity as complex.

### **1.3 Northern Ireland**

In Northern Ireland, clinical psychologists in particular play a pivotal role in determining intellectual disability, and very often act as gatekeepers to what have for many years been combined (health and social services) Adult Intellectual Disability Services.

The Mental Health (Northern Ireland) Order 1986 remains operative in Northern Ireland, although it is currently under review. This recognises three distinct categories of intellectual disability: ‘mental handicap’; ‘severe mental handicap’; and ‘severe mental impairment’. ‘Mental handicap’ is defined as ‘a state of arrested or incomplete development of mind which includes significant impairment of intelligence and social functioning’. ‘Severe mental handicap’ is defined in exactly the same way, save that the impairments of intelligence and social functioning are ‘severe’ rather than ‘significant’. And ‘severe mental impairment’ is defined in exactly the same way as ‘severe mental handicap’, save that there is an additional requirement that it ‘is associated with abnormally aggressive or seriously irresponsible conduct on the part of the person concerned’. ‘Severe mental impairment’ is, therefore, defined exactly as in the Mental Health Act 1983. However, unlike the 1983 Act, the Mental Health (Northern Ireland) Order 1986 has no category of ‘mental impairment’. Apart from mental illness, the only ground for guardianship it recognises is ‘severe mental handicap’, and the only ground for detention in hospital for treatment is ‘severe mental impairment’. In both cases, therefore, *severe* impairments of both intelligence and social functioning have to be demonstrated – and psychologists are often asked to conduct assessments with a view to determining whether individuals display such levels of impairment.

There is currently no provision within Northern Ireland for explicit capacity legislation, other than case law. However, it is anticipated that the legislation that will replace the current Mental Health (Northern Ireland) Order 1986 will apply, within a single legislative framework, not just to matters of mental health, but to wider health and social care provision and to financial matters as well. The test for capacity is likely to be broadly the same as applies in the Mental Capacity Act 2005, so it is anticipated that psychologists will play a significant role within the new legislation once it comes into effect.

## Section 2: Defining intellectual disability

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Many of the contexts identified above involve their own, specific definitions of intellectual disability (or related terminology), and psychologists should adhere to these when carrying out assessments to determine whether or not the requirements of those definitions are fulfilled. Generally, and where no specific definition is involved, the Society recommends that a diagnosis of intellectual disability requires the demonstration of three essential criteria:

- significant impairment of intellectual functioning;
- significant impairment of adaptive behaviour; and
- onset before adulthood.

These three criteria are perhaps most readily identifiable in the most recent definition proposed by the American Association on Intellectual and Developmental Disabilities (*AAIDD-11*):

*Intellectual disability is characterised by significant limitations both in intellectual functioning and in adaptive behaviour as expressed in conceptual, social and practical adaptive skills.*

*This disability originates before age 18.*

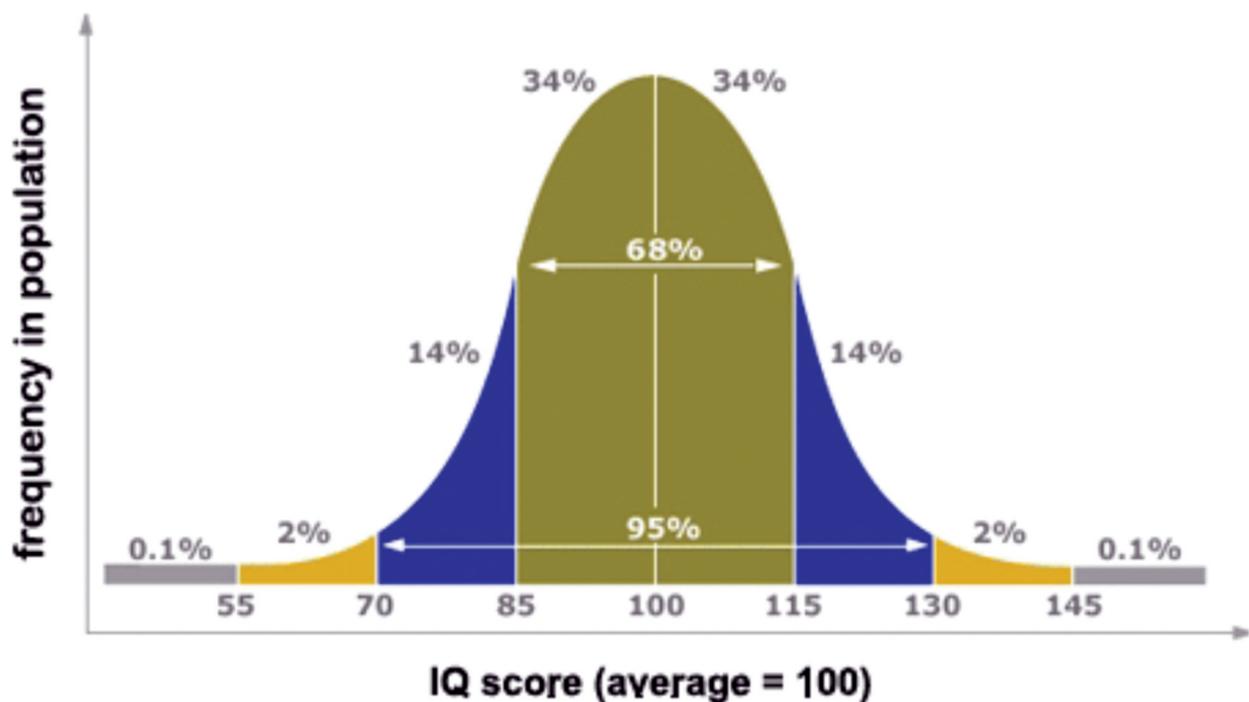
This section considers each of the three essential criteria for intellectual disability in more detail. The first refers to intellectual functioning, the second to adaptive behaviour (social functioning) and the third to age of onset.

### 2.1 Significant impairment of intellectual functioning

Considerable debate and disagreement continues regarding the definition of intelligence. *AAIDD-11* defines it as ‘a general mental ability [which] includes reasoning, planning, solving problems, thinking abstractly, comprehending complex ideas, learning quickly and learning from experience’. This reflects the general consensus of research findings presently, which support a hierarchical model of intelligence (Whitaker, 2013). It assumes a general factor of intelligence that can be summarised as a single figure (generally, the ‘intelligence quotient’, or IQ) which in turn is comprised of a number of semi-independent factors that are highly correlated with IQ and, to a lesser extent, with each other.

IQ scores are determined by reference to a normal distribution within the population, generally with a mean of 100 and a standard deviation (SD) of 15. The majority – just over two-thirds – of the general population may be expected to fall within one SD either side of the mean (that is, within the IQ range 85 to 115). As scores deviate further from the mean, in either direction, the numbers in the population with corresponding levels of IQ become progressively smaller. This is demonstrated by the normal distribution curve. However, there is in practice a ‘bump’ at the lower end of the IQ distribution, resulting in a relative over-representation of individuals with IQs below about 50 to 55 in particular. This is attributable to a much higher frequency of organic and/or genetic factors amongst those at the lower end of the distribution, and represents an additional 0.5 per cent (approximately) of the population with IQs at the very lowest levels.

For several decades now, it has been accepted generally that a ‘significant impairment of intellectual functioning’ is best represented by an IQ score derived from an appropriately standardised and norm-referenced assessment measure that is more than two SDs below



the population mean, allowing for the expected level of measurement error within the test (see below, Section 4.1). On tests with a mean of 100 and a SD of 15, this equates to an IQ of less than 70 approximately. This is the criterion recommended by all three major international classification systems currently (*DSM-5*, *ICD-10* and *AAIDD-11*). It is also the criterion recommended by the British Psychological Society. Based upon the normal distribution curve, and allowing for the previously mentioned ‘bump’ at the lower end of that curve, this means that just over 2.5 per cent of the general population may be expected to have a level of intelligence commensurate with a diagnosis of intellectual disability.

In the United Kingdom it is almost exclusively the role of applied psychologists to undertake the individualised psychometric assessments which produce the IQ scores considered valid for the purpose of establishing a diagnosis of intellectual disability. This has been a longstanding role for psychologists, who receive specific training in the administration, scoring and interpretation of intelligence tests.

## 2.2 Significant impairment of adaptive behaviour

Appreciation of the term adaptive behaviour has evolved over the years and, based upon a number of factor analytic studies dating back to the 1960s (Tassé et al., 2012), there is currently a broad consensus as to what it involves. Thus *AAIDD-11* defines ‘adaptive behaviour’ as ‘the collection of conceptual, social and practical skills that have been learned and are performed by people in their everyday lives’, while *DSM-5* says that ‘adaptive functioning’ concerns ‘activities of daily life’ and ‘involves adaptive reasoning in three domains: conceptual, social and practical’.

These two major classification systems each include a number of skills as examples of the three major domains of functioning, and although these lists are not identical, there is considerable overlap between them. Thus, for example, *AAIDD-11* presents the following as examples of skills comprising each of the three domains:

- *Conceptual skills*: language; reading and writing; and money, time and number concepts;
- *Social skills*: interpersonal skills, social responsibility, self-esteem, gullibility, naivety (i.e. wariness), follows rules/obeys laws, avoids being victimised, and social problem-solving;
- *Practical skills*: activities of daily living (personal care), occupational skills, use of money, safety, health care, travel/transportation, schedules/routines, and use of the telephone.

Only relatively recently have measures been developed for the assessment of adaptive behaviour (certainly, as defined in terms of these three key domains of functioning) that are norm-based and that have been standardised on a representative sample of the general population. It is, therefore, possible now to assess and report upon adaptive behaviour in much the same way as it has for many years been possible to do for intellectual functioning. That being the case, and in line with *AAIDD-11* in particular, the Society recommends that a ‘significant impairment of adaptive behaviour’ is best represented by a score derived from an appropriately standardised and norm-referenced assessment measure that encompasses either: (i) any one; or (ii) all three of the domains of conceptual, practical and social skills that is more than two SDs below the population mean, allowing for the expected level of measurement error within the test concerned (see below, Section 4.1). On tests with a mean of 100 and a SD of 15, this equates to a score of less than 70 approximately.

Given that measures for the assessment of adaptive behaviour are increasingly norm referenced and psychometrically based, the Society recommends that assessments of adaptive behaviour, just as those of intellectual functioning, should be carried out by appropriately qualified psychologists who are skilled in the assessment of adults who may have an intellectual disability. Psychologists who undertake assessments of adaptive behaviour should meet the criteria required by the publishers and distributors of the tests, and be registered with the HCPC.

### 2.3 Age of onset prior to adulthood

*DSM-5* defines the last of its three essential criteria for intellectual disability as follows: ‘Onset of intellectual and adaptive deficits during the developmental period’.

*AAIDD-11* is more explicit: ‘This disability originates before age 18’.

Accordingly, the Society recommends that, for the criterion ‘onset before adulthood’ to be met, there should be evidence of the presence of each of the other two criteria in the period before the person attains (or attained) the age of 18 years.

### 2.4 Levels of intellectual disability

Until relatively recently, it was common to identify, specifically on the basis of IQ, four discrete levels of intellectual disability – mild, moderate, severe and profound. *ICD-10* still adheres to this practice, although it is anticipated that the forthcoming *ICD-11* will not. Certainly, sub-classification on the basis of IQ alone was abandoned in favour of an individual’s intensity of support needs in *AAIDD-9* (1992), while *DSM-5* proposes a system of sub-classification (again, mild, moderate, severe and profound) that is based upon adaptive functioning rather than IQ.

The Society endorses the view that there is generally little to be gained from sub-classifying persons with intellectual disability on the basis of IQ alone. However, it recognises that there may be occasions when it is appropriate to distinguish between levels of intellectual disability – such as when seeking to highlight an individual’s level of support-needs, for example, or when there is a legal requirement for such distinction to be made (as arises with specific aspects of the Mental Health (Northern Ireland) Order 1986, for example – see above, Section 1.3). Specifically, the Society accepts that it may at times be appropriate for psychologists and other clinicians to distinguish between ‘intellectual disability’ and ‘severe intellectual disability’.

Whereas intellectual disability is defined as comprising ‘significant’ impairments of both intelligence and adaptive behaviour (both impairments evident before adulthood), the criteria for severe intellectual disability are as follows:

- severe impairment of intellectual functioning;
- severe impairment of adaptive behaviour; and
- onset before adulthood.

Operationally, the Society recommends that, whereas ‘significant’ impairments are best represented by scores derived from appropriately standardised and norm-referenced assessment measures of intelligence and adaptive behaviour that fall more than two SDs below the population mean (allowing for the expected level of measurement error within the tests concerned), ‘severe’ impairments are those that fall more than three SDs below the mean on such measures. On measures with a mean of 100 and a SD of 15, this latter equates to scores of less than 55 approximately.

## Section 3: Assessing Intellectual Disability

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### 3.1 Gathering preliminary information

An individual's account of his/her history and any past or current difficulties, alongside his/her behaviour in the course of an assessment interview, can provide important information regarding the presence, nature and impact of any cognitive difficulties that he/she may have (Spreeen & Strauss, 1998). Therefore, taking a detailed background history may be invaluable in assessing whether or not a person has an intellectual disability. Not only may crucial historical details be secured during an interview, but information can be gained about the individual's general appearance, eye contact, use of vocabulary, social interaction, and so on. However, it is usually beneficial to have this information supplemented, where possible, by information from other sources too.

Such an interview does not necessarily follow a fixed format, albeit it is generally useful for it to cover the following:

- Family and social history;
- Developmental history (birth, pregnancy, developmental milestones);
- Health problems as a child;
- Input from other professionals, both as a child and as an adult;
- Educational history (types of schools, statements of special educational needs);
- Occupational history (both paid and voluntary);
- Medical history (physical and psychological difficulties, head injury, epilepsy);
- Mental health issues;
- History of emotional care and support (including known attachment difficulties);
- Significant bereavements;
- Family interpretations of the person's difficulties;
- Previous cognitive assessments (seeing the original reports, if possible);
- Current medication;
- Vision and hearing;
- Language;
- Motor difficulties;
- Cultural issues.

Several of these can have a direct bearing upon, and can therefore assist in determining whether, the last of the three criteria for intellectual disability in particular has been met.

### 3.2 Selecting appropriate assessment measures

#### *Measures for the assessment of intellectual functioning*

Ideally, only the most recent versions of measures of intellectual functioning that fulfil all four of the following criteria should be used in an assessment of intellectual disability:

- they should be designed for individual (not group) administration;
- they should have been constructed on the basis of the normal distribution of general intelligence, and standardised using a representative sample of adults from across the United Kingdom;
- they should possess psychometric properties (reliability and validity) that lie within the range of scientific acceptability; and

- they should be based upon a multidimensional, hierarchical model of intelligence, producing not just an overall score but also related index or composite scores.

There exists currently just one assessment measure that fulfils all four of these criteria: the *Wechsler Adult Intelligence Scale – Fourth UK Edition (WAIS-IV UK)* (Wechsler, 2010). This is the latest version of what has for many years been the most widely used measure of assessment of adult intelligence in the United Kingdom. Accordingly, the Society recommends that the *WAIS-IV UK* should be the test of choice in assessments of a person’s level of intellectual functioning. In addition to a Full-scale IQ (FSIQ), it produces four index scores – Verbal Comprehension (VCI), Perceptual Reasoning (PRI), Working Memory (WMI) and Processing Speed (PSI) – all from 10 core subtests. (A further five, optional subtests are available for substitution or more detailed assessment.) The *WAIS-IV UK* has been normed for use with persons aged 16 to 90 and, uniquely amongst similar measures, it was standardised on a sample of 270 United Kingdom adults. Test-retest reliability for the American sample has been reported at 0.96. However, there is evidence to suggest that *WAIS-IV UK* test results may be less accurate in the lower ranges of ability (Whitaker, 2012).

It may not always be either appropriate or possible to use the *WAIS-IV UK* with a particular individual, in which case the psychologist involved may wish to consider an alternative means of assessing the person’s level of intellectual functioning. Especially in cases where time is limited or when the person is known to have limited powers of concentration, the *Wechsler Abbreviated Scale of Intelligence, Second Edition (WASI-II)* (Wechsler, 2011) may be considered. However, this employs just a small number of subtests (four, or even just two) so, despite its reporting both Verbal and Performance IQs in addition to a FSIQ, it is doubtful if the *WASI-II* could be said to fulfil the criterion of a multidimensional, hierarchical model of intelligence. Nevertheless, the *WASI-II* can certainly be useful on occasions, particularly in circumstances where it is not possible to administer a *WAIS-IV* and/or for screening purposes. (Its scores may be transferred and incorporated directly into a subsequently-completed *WAIS-IV*, from which those subtests already completed as part of the *WASI-II* can therefore be omitted.) In cases where the individual being assessed does not have an adequate use of English, the *Leiter International Performance Scale, Third Edition (Leiter-3)* (Roid, Miller et al., 2013) may be considered as an alternative to the *WAIS-IV UK*. This is the latest version of a completely non-verbal test of intelligence, which is claimed to be culture-free. However, it has not been standardised in the United Kingdom and concerns have been expressed about the accuracy and reliability of earlier versions of the scale, particularly in the lower ranges of ability (Glenn & Cunningham, 2005).

Whatever the assessment measures employed, the psychologist concerned should at all times be mindful of their specific limitations and should take care to administer them and interpret their results accordingly. Also, as already indicated, psychologists should ensure that they always use only the most recent versions of any tests they employ.

### ***Measures for the assessment of adaptive behaviour***

Avery and Sullivan (2013) highlight that the assessment of adaptive or social behaviour is less clearly defined than that of assessing intellectual functioning, and that there is no clear agreement on how adaptive behaviour should be assessed or on which is the best assessment measure to use for that purpose. Typically, measures of adaptive behaviour comprise a series of items reflecting a number of specific skill domains. Most recently, these domains have been defined as comprising conceptual, social and practical skills.

Respondents are asked to indicate whether, and to what extent, the person being assessed performs each of a series of behaviours in the course of their daily lives. Although the individual being assessed may also serve as the respondent, it is generally advisable that some other person – but who nevertheless knows the individual well – be approached to provide the necessary information. The results are typically presented as a score for each domain separately and for the scale as a whole.

Ideally, any measures of adaptive behaviour that are employed as part of an assessment of intellectual disability should comply with each of the following:

- they should have been constructed on the basis of an essentially normal distribution of adaptive behaviour, and standardised using a representative sample of adults from across the United Kingdom;
- they should possess psychometric properties that lie within the range of scientific acceptability;
- they should be based upon a multidimensional, hierarchical model of adaptive behaviour, producing not just an overall score but also composite scores in respect of each of the conceptual, social and practical domains;
- they should be appropriate for the age, gender, socio-cultural background, religion and community setting of the person who is being assessed; and
- they should be completed by someone who knows the person being assessed very well – and only exceptionally by that individual him/herself.

A number of measures for the assessment of adaptive behaviour are currently available, but unfortunately none of them complies fully with all of the above. Two come closest: the *Adaptive Behaviour Assessment System, Second Edition (ABAS-II)* (Harrison & Oakland, 2003) and the *Vineland Adaptive Behaviour Scales, Second Edition (Vineland-II)* (Sparrow, Cicchetti & Balla, 2005). Each of these is available in multiple forms, according to the relationship between the respondent and the person being assessed, and each has adequate psychometric properties. They both are based on scales where the mean is 100 and the SD is 15 – so they both allow for a ready determination of whether any given score falls more or less than two SDs below the mean. However, both have been standardised using representative samples of the American general population only. A major difference between the two measures is in the organisation of the skills they assess. The *Vineland-II* comprises three main sections (Communication, Daily Living, and Socialisation), whereas the *ABAS-II* addresses 10 adaptive-skill areas across the three domains of Conceptual, Social, and Practical skills. The *ABAS-II* is likely to be the more directly relevant to the current definition of intellectual disability, therefore. Nevertheless, the *Vineland-II* has certain advantages as well – not least its ability to present an individual's raw scores as 'age-equivalents' (albeit age-equivalents must always be interpreted with caution). Psychologists should bear in mind both the strengths and weaknesses of the two measures, as well as the purposes for which they are to be used, when deciding upon which to adopt in any particular situation.

Other measures for the assessment of adaptive behaviour are also available. These tend not to be based upon a normal distribution, however, nor have they been constructed with the key domains of Conceptual, Social, and Practical skills directly in mind. For a recent review of measures of adaptive functioning, see Tassé et al. (2012).

As with measures for the assessment of intellectual functioning, psychologists conducting assessments of adaptive behaviour should at all times be mindful of the specific limitations of any tests they use, and they should take care to administer such tests and interpret their results accordingly. Also, psychologists should ensure that they always use only the most recent versions of any tests they employ.

### 3.3 Conducting an assessment

A number of factors need to be borne in mind when conducting assessments of either intellectual functioning and/or adaptive behaviour. These are discussed below, in turn.

#### *Factors in the assessment of intellectual functioning*<sup>2</sup>

##### *The Setting/Environment*

There is very little research on the effect of the environment on cognitive ability. However, it is known that unfavourable conditions not only affect well-being but also mental performance (Klatte, Wegner & Hellbrück, 2005). The *WAIS-IV* manual highlights that testing should take place in a well lit, quiet room that is free from distraction. It also describes suitable seating and how to set up the test materials.

##### *Mental health*

The relationship between specific psychiatric diagnoses and performance on tests of intellectual abilities is neither straightforward nor well understood: people with the same diagnosis may be affected in different ways, and the same individuals may be affected in different ways at different times. Self-evidently, assessments should not be conducted with individuals who are distressed or who are not oriented to place and time. As a general rule, however, testing conducted either during or immediately after a period of detention under mental health legislation should be avoided if at all possible, since the results obtained are unlikely to be either valid or reliable. Likewise, assessments should generally not be carried out either just before or just after a woman gives birth (as may be requested in relation to child care proceedings, for example): the results of such assessments too could be questioned in terms of their validity.

##### *Medication*

There is growing evidence that many pharmacological agents – whether prescription, over-the-counter or illegal – can influence neuropsychological functioning (Hartman, 1995). It is unclear to what extent such medications may influence the performance of any one individual at a particular time. However, it is generally accepted that any medication will have its greatest effect upon an individual's performance during the first few weeks of its prescription and for two weeks after its withdrawal. This should be taken into account when an assessment is being planned.

##### *Fatigue*

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

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<sup>2</sup> This section discusses a number of personal and environmental factors that may impact upon the administration of a test of general intellectual functioning with a given individual. A list of other, higher-level factors that may impact upon the assessment of intelligence are discussed in *AAIDD-11* (pages 35–41).

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.

#### *Motivation*

For test results to be considered valid, it is important that the individual being assessed gives of his/her best throughout the assessment process. Each of the factors already identified can affect motivation. So too can the context of a person’s referral for assessment, including who has requested the assessment and for what purpose. It is, therefore, important that the psychologist addresses carefully the issue of consent throughout the process. Specifically, if an individual objects to an assessment, even though it may be in his/her best interests for that assessment to proceed, this could significantly affect the results obtained. Clearly, a valid assessment cannot be completed against an individual’s will or where any form of coercion is involved.

#### *Effort*

In some circumstances, an individual 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). Where this is suspected, the psychologist should consider and, where indicated, formally assess the person’s effort throughout the assessment. This should be done in line with guidance in the Society’s 2009 publication, *Assessment of Effort in Clinical Testing of Cognitive Functioning for Adults*.

#### *Language, culture and ethnicity*

It is becoming increasingly common for psychologists to be asked to assess persons who do not have English as their first language. The validity of such assessments can be problematic, for a variety of reasons: rapport can be hard to establish and there can be difficulties in relaying specific test instructions – neither of which will necessarily be ameliorated by the use of interpreters and/or non-verbal assessment materials;<sup>3</sup> persons educated abroad may have had limited educational opportunities and/or experience of formal assessments and may be suspicious of same; and 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 persons from other cultures or populations may be disadvantaged when presented with them. All of these increase the likelihood of someone being diagnosed with an intellectual disability who does *not*, in reality, fulfil the criteria for that label. 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;

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<sup>3</sup> The *WAIS-IV UK* manual covers some of the issues that need to be considered when using interpreters and when assessing across communication modalities, including the use of sign language, simultaneous communication, cued speech and aural/oral communication.

- 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, and this could invalidate the results);
- Highlight the above difficulties, particularly in respect of how they have impacted upon the interpretation of any test results obtained, in clinical reports.

#### *Sensory and other impairments*

The *WAIS-IV* manual warns against attributing poor performance on cognitive tests to low intellectual ability when in fact some form of physical, language and/or sensory difficulties may be responsible. Clinicians need to be aware that there may need to be adaptations made when assessing individuals with these additional difficulties. The *WAIS-IV* manual recommends 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 below, Section 4.1) should be applied to evaluate the effects of any such modifications on the scores obtained. However, the verbal subtests of the *WAIS-IV* can be administered equally to persons with and without a visual impairment. Also, the *WAIS-IV* manual lists a number of issues that should be considered when testing individuals who are deaf or have hearing impairments.

#### *Factors in the assessment of adaptive behaviour*

The aim of an assessment of adaptive behaviour is to indicate the extent to which a person can function independently. Ideally, estimates of adaptive behaviour should be provided by third-party informants who know the person well and are familiar with his/her functioning in daily living. However, measures of adaptive behaviour are open to the personal biases of informants (who may either wittingly or unwittingly underestimate the person's abilities in an attempt to obtain services, for example, or overestimate them through a reluctance to acknowledge the person's limitations) and psychologists should employ clinical judgement to interpret the scores that are derived accordingly. One safeguard against such bias is to secure assessments of the person's adaptive behaviour from informants across more than one setting (e.g. home and work). In addition, it may be helpful to undertake some direct observation and/or assessment of the individual. Conceptual skills such as reading, spelling and numerical skills, for example, may be assessed directly through specific tests of these skills.

## Section 4: Interpreting the results of an assessment

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This section concerns the interpretation of data collected throughout an assessment, particularly in relation to whether the individual concerned fulfils the criteria for a diagnosis of intellectual disability, but also in relation to other clinically significant insights that the data might provide.<sup>4</sup>

In relation to a diagnosis of intellectual disability, the key concern is whether the person has significant impairments of both intellectual functioning and adaptive behaviour, acquired before adulthood. Essentially, ‘significant’ here means more than two SDs below the population mean; ‘intellectual functioning’ refers to a Full-scale IQ score; ‘adaptive behaviour’ refers to a score on a standard measure of Conceptual, Social, Practical or General adaptive behaviour skills; and ‘before adulthood’ means prior to the age of 18 years.

The overall determination, based on all three criteria, will be one of the following:

- that the person fulfils the criteria for intellectual disability;
- that the person does not fulfil the criteria for intellectual disability; or
- that it has not been possible to determine whether or not the persons fulfils the criteria for intellectual disability.

The assessment should also consider the profile of scores produced by the individual, and the significance of any discrepancies there may be between those scores.

### 4.1 Clinical judgement

Interpreting the results of assessments of intellectual functioning and adaptive behaviour requires the psychologist to exercise ‘clinical judgement’. This is defined by *AAIDD-11* as ‘a special type of judgement rooted in a higher level of clinical expertise and experience. It emerges directly from extensive data and is based on training, experiences, and specific knowledge of the person and his or her environment’ (p.85). Essentially, it is the application by the psychologist of his/her knowledge of the tests, the scores and what they mean, their knowledge and expertise in relation to intellectual disability, and their clinical observation of the person whom they are assessing currently, to arrive at a conclusion that is transparent in its reasoning and justifiable both to the person being assessed (where possible) and to external parties.

Crucially, the psychologist needs to consider the extent to which the derived scores are likely to reflect the person’s ‘true’ abilities. A number of factors must be considered, including the fact that test scores always carry a margin of error. This is usually presented in normative tables as a 90 per cent or 95 per cent confidence interval (i.e. the range of scores within which there is a 90 per cent or 95 per cent probability that the person’s true score is located). These confidence intervals, which are generally reported in test manuals, are derived from a statistical model that assumes a normal distribution of scores within the population. However, for most tests they are based primarily upon data from a sample of the general population that under-represents the ‘bump’ at the lower end of the distribution curve (see above, Section 2.1). This means that the margin of error for a

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<sup>4</sup> Clinicians should also be aware that there may be a need to support individuals when a diagnosis of intellectual disabilities is made. They will need to explain what it means and recognise that the individual may need assistance in both understanding what the diagnosis means and how to adjust to it.

person's true score at that extreme of the distribution is likely to be greater than the published confidence intervals suggest. Some empirical evidence supports this inference in relation to the Wechsler tests in particular (e.g. Whitaker, 2013).

As part of the exercise of clinical judgement, it is important for the psychologist to interpret any information gathered about the person's history alongside any factors from that history that may have influenced the person's performance on the tests attempted subsequently, such as deprivation, a chaotic upbringing or later life, abuse, etc. (see above, Section 3.1). These factors do not necessarily negate the possibility of an intellectual disability, but they may contribute to the person's functioning in an impaired manner. It is also important to record and take account of relevant factors concerning the tests employed and the ways in which those tests are believed to measure intellectual functioning and adaptive behaviour respectively (Section 3.2). Finally, it is important to interpret and take account of qualitative observations of the person's engagement with and approach to the tests presented (Section 3.3), for example, Did they work hard? Were they persistent? Did they use trial-and-error or other strategies? Did they talk themselves through the test? Did they appear anxious? Did they comment on how they were doing?

## 4.2. Significant impairment of intellectual functioning

On standard tests of intellectual functioning, this amounts to whether the person's 'true' IQ is likely to fall above or below the cut-off of two SDs below the population mean.

In other words, is the person's true IQ likely to be at least 70, or is it more likely to be 69 or below? There are four possibilities here:

- If the derived score is well below 70, such that even the top of the selected confidence interval for the score is no higher than 69, then, providing there are no compelling reasons from the person's history or performance on the test to suggest otherwise, it may be concluded that the criterion for a 'significant impairment of intellectual functioning' has been met.
- If the derived score is well above 70, such that the bottom of the selected confidence interval for the score is no lower than 70, then, providing again there are no compelling reasons from the person's history or performance on the test to suggest otherwise, it may be concluded that the criterion for a 'significant impairment of intellectual functioning' has not been met.
- In all other eventualities, including where the derived score falls very close to 70, such that the selected confidence interval includes both 69 *and* 70, the psychologist must exercise clinical judgement to determine the person's true IQ, and from that to establish whether or not the criterion for a 'significant impairment of intellectual functioning' has been met.
- Exceptionally, even with the exercise of clinical judgement, it may not be possible for the psychologist to reach a determination as to whether or not the criterion of a 'significant impairment of intellectual functioning' has been met.

Broadly speaking, whereas there are many factors that may decrease performance and so lead to an under-estimate of IQ, there are very few that can increase performance and thereby lead to an over-estimate of IQ. As indicated above (Section 3.3), factors that can decrease performance include an inappropriate (e.g. noisy) testing environment, stress or anxiety, depression or other mental health problems, attention problems, medication,

fatigue, low self-esteem or self-confidence, visual, auditory or other physical disabilities, and reduced effort. In contrast, the only major factors associated with over-estimates of IQ are ‘teaching to the test’ (coaching) for verbal subtests and too short a test-retest interval for performance (non-verbal) subtests.

If any of the factors known to influence performance on tests of intellectual functioning are suspected (Section 3), further assessment may be prompted and the matter should be discussed in the subsequent report of that assessment (Section 5). Evidence of such influence may be present in the profile of subtest scores. For example, the influence of depression is greater on subtests requiring rapid performance (e.g. digit symbol substitution), while that of attention-deficit is greatest on tests requiring sustained attention (e.g. digit span). If a specific relationship is identified (for example, an individual who has been identified as depressed does show a specific weakness on timed tests), then the derived IQ score should be recomputed omitting the anomalous subtest(s). The purpose of such a re-calculation is to give the psychologist an indication of the extent to which the original IQ estimate may be biased: it feeds into the psychologist’s clinical judgement, although it should never substitute for the original estimate, which should always be reported.

As well as considering a person’s Full-scale IQ, it is good practice to interpret the derived index scores, any discrepancies between them, and any strengths or weaknesses in individual subtests. A good report should provide not only a ‘verdict’ on whether or not a person fulfils the criteria for a ‘significant impairment of intellectual functioning’, but also an analysis of the full test profile.

### **4.3 Significant impairment of adaptive behaviour**

Unlike intellectual functioning, adaptive behaviour is generally assessed indirectly by psychologists, using third-party reports. This requires that the psychologist is able to identify an informant who knows the individual sufficiently well to provide reliable data. It follows that an assessment should not be conducted in the absence of a reliable informant, in which case a direct (observational) assessment of the individual’s adaptive behaviour may be required instead.

Generally, though, as with intellectual functioning, a ‘significant impairment of adaptive behaviour’ is best understood as a level of performance on a standard measure that is more than two SDs below the general population mean. On measures where the mean is 100 and the SD 15, this equates to a score of less than 70. Unlike with intellectual functioning, however, where this applies to just a single, overall score (the Full-scale IQ), such a level of performance in respect of any one of four possible areas – Conceptual, Social, Practical or General (overall) adaptive skills – is sufficient for the criterion of a ‘significant impairment of adaptive behaviour’ to be met. This means that any differences that are found within an individual’s profile of adaptive behaviour abilities, whilst undoubtedly informative, will have only a limited impact on the decision as to whether or not the criterion for a ‘significant impairment of adaptive behaviour’ has been met.

Again, it is the individual’s ‘true’ level of performance that is the crucial factor and, also again, there are four possibilities within the realm of adaptive behaviour:

- If the derived score in *any one* of the four domains of Conceptual, Social, Practical or General adaptive skills is well below 70 (regardless of performance in the other three), such that even the top of the selected confidence interval for that score is no higher

than 69, then, providing there are no compelling reasons to suggest that the person's true level of performance is other than this, it may be concluded that the criterion for a 'significant impairment of adaptive behaviour' has been met.

- If the derived score in *all four* of the above areas is well above 70, such that the bottom of the selected confidence interval for all four scores is no lower than 70, then, providing there are no compelling reasons to suggest that the person's true level of performance is other than this, it may be concluded that the criterion for a 'significant impairment of adaptive behaviour' has *not* been met.
- In all other eventualities, including where any (or all) of the derived score(s) are very close to 70, such that the selected confidence interval includes both 69 and 70, the psychologist must exercise clinical judgement to determine the person's true level of adaptive behaviour, and from that to establish whether or not the criterion for a 'significant impairment of adaptive behaviour' has been met.
- Exceptionally, even with the exercise of clinical judgement, it may not be possible for the psychologist to reach a determination as to whether or not the criterion of a 'significant impairment of adaptive behaviour' has been met.

Using clinical judgement, the psychologist should seek to establish if any impaired functioning on the part of the individual being assessed is due to an intellectual disability or if it could be due instead to some other cause, such as a physical or sensory disability, mental illness, ADHD, or substance abuse, for example. If an alternative account of the impairment is suspected, this should trigger further assessment (e.g. a mental health screening), which in turn may lead to the individual being signposted towards services other than specialist Intellectual Disability Services. If further assessment identifies factors additional to intellectual disability that are potentially remediable (e.g. mental health problems), then this raises the possibility that whilst the individual fulfils the criterion for impairment of adaptive behaviour at this time, his/her adaptive functioning might improve in the future to the point where the criterion would not be met. This prospect clearly will depend upon the extent of the current impairment, and clinical judgement should be used when deciding on how this matter should be reported.

#### **4.4 Age of onset prior to adulthood**

This criterion is understood operationally as an age-of-onset prior to the individual's eighteenth birthday. This means that there should be evidence of the presence of each of the other two criteria before the person attains the age of 18 years. Such evidence will often be available from those individual(s) providing information on the person's adaptive behaviour and/or background details, with other possible sources including historical educational, developmental and medical records, for example.

After considering the available evidence, the psychologist should determine whether this third criterion for an intellectual disability has or has not been met. Only very exceptionally should it prove impossible to come to one of these determinations. For example, in cases where no direct evidence of the age-of-onset criterion can be found (such as may occur when an individual's first encounter with Services is as an adult), then, if an assessment identifies the presence of impairments both of intellectual functioning and adaptive behaviour it will usually be reasonable to conclude that those impairments are long-standing and, therefore, that the criterion has been met. Exceptions to this

include situations where there is evidence of events that could have compromised brain functioning (for example, a road traffic accident, a stroke or serious mental illness) having occurred only after the age of 18 years.

#### **4.5 Severe intellectual disability**

The criteria for severe intellectual disability are identical to those for intellectual disability, save that the impairments of intellectual functioning and adaptive behaviour must be 'severe' rather than 'significant'. This means that the cut-off for scores on standard measures of both intellectual functioning and adaptive behaviour for the criteria of a 'severe impairment of intellectual functioning' and a 'severe impairment of adaptive behaviour' respectively are set at 55 rather than 70. In all other respects, the processes for deciding upon whether an individual fulfils the criteria for severe intellectual disability are exactly as detailed above, in Sections 4.2 to 4.4, for intellectual disability.

#### **4.6 The need for concurrence of the three criteria**

Intellectual functioning and adaptive behaviour are not highly correlated: in adults, the correlation may be as low as 0.2 (Sparrow et al., 2005), although somewhat higher correlations, of around 0.5, have been reported in children (Whitaker, 2013). This is reflected in the fact that of the just over 2.5 per cent (approximately) of the population whose IQs are believed to be under 70, just a quarter to a third are known to Intellectual Disability Services; this implies that many people with this level of cognitive ability are nevertheless able to function adequately in their everyday lives and so do not fulfil the criterion of a 'significant impairment of adaptive behaviour'. Conversely, there are many people whose adaptive behaviour is impaired but whose IQs are above 70, who are known to services as 'vulnerable adults', and who fulfil the criteria for certain other conditions, such as autistic spectrum disorder, personality disorder, etc. (It is generally true that people who are referred to services have deficits in their adaptive behaviour; indeed this usually is the reason why they need help and are referred in the first place.)

For a diagnosis of intellectual disability (or severe intellectual disability) to be made, all three of the essential criteria, separately, must be fulfilled. This means that someone with a *significant* (or even *severe*) impairment in one of the two domains of functioning only (i.e. intellectual functioning and adaptive behaviour), and with no significant impairment in the other, may not be adjudged to have an intellectual disability. Similarly, for *severe* intellectual disability, severe impairments of *both* intellectual functioning and adaptive behaviour must be evident.

It is ideally essential, therefore, that when seeking to determine whether or not a person has an intellectual disability, assessments should be carried out both of intellectual functioning *and* of adaptive behaviour. However, it is recognised that this may not always be possible (for example, when a physical disability prevents an IQ assessment or when no appropriate informant can be found to provide the information necessary for an assessment of adaptive functioning). In cases where it is possible to undertake only one half of the recommended assessment (i.e. of intellectual functioning or adaptive behaviour), the psychologist must employ clinical judgement to reach an overall determination, and this should be made clear in any subsequent report. Note that this form of assessment is not recommended, however, and should be undertaken only in exceptional circumstances.

## Section 5: Reporting on assessments

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It is likely that most reports prepared by psychologists within the area of intellectual disability address the issue of whether or not a person may be said to have an intellectual disability – that is, whether or not he/she fulfils the three essential criteria of significant impairments of both intellectual functioning and adaptive behaviour, both of which become evident before the age of 18 years. It may be that this is the only reason for an assessment – to determine a person’s eligibility for Intellectual Disability Services, for example. Often, however, there may be other reasons as well – such as determining a person’s ‘capacity’ in relation to a particular matter (Section 1). Both the amount and nature of the information that is derived will vary accordingly, and that in turn will impact upon the format and content of any report that is prepared subsequently.

Most of the guidance provided in this section concerns the reporting of assessments undertaken to determine the presence or absence of intellectual disability. However, reference will be made where appropriate to assessments carried out for other purposes too. Whilst recognising that the content and presentation of any report may be influenced by local circumstances and is ultimately at the discretion of the psychologist involved, the Society recommends that reports on assessments within the area of intellectual disability should consider the following areas (cf., Lichtenberger & Kaufman, 2013):

- Identifying information;
- Reason for referral;
- Background information;
- Appearance and behavioural observations;
- Tests administered;
- Test results and interpretation;
- Summary, diagnostic impression and recommendations.

### 5.1 Identifying information

The report should present information identifying the person being assessed, including his/her name, age, gender, date of birth and address. It is essential that these details are reported clearly and accurately. If the person is known by more than one name, then all names used should be reported.

### 5.2 Reason for referral

The report should state both the source of the referral and the reason(s) for it. Also, the issues to be addressed within the report – which will not necessarily be the same as those highlighted in the referral (in which case the reasons for any discrepancies should be given) – should be summarised. For example, if the assessment set out to determine whether or not a person has an intellectual disability (or, in certain circumstances, a severe intellectual disability), the three essential criteria should be summarised: (i) a significant (or severe) impairment of intellectual functioning; (ii) a significant (or severe) impairment of adaptive behaviour; and (iii) onset before adulthood.

### 5.3 Background information

The report should summarise any relevant information in relation to the individual prior to the current assessment. This may include developmental, medical (including other diagnoses), sensory, educational and vocational information, as well as current living and support arrangements and the results of any previous assessments. Such information may not be available in every case, of course.

Issues of consent should also be addressed in the report – in particular, whether the subject of the assessment had provided consent before the referral and/or at the time of the initial appointment or, in the event of his/her not being able to provide valid consent, the basis on which the assessment has proceeded in his/her best interests.

Finally, the date and venue of any appointment(s) arranged both with the person being assessed and/or with anyone acting as informant on his/her behalf should be specified.

### 5.4 Appearance and behavioural observations

The person's presentation both initially and throughout the assessment should be described, with particular emphasis on any factors that might have impacted upon his/her performance on the tests attempted.

### 5.5 Tests administered

Since all three criteria for intellectual disability must be met before a determination can be made, it is necessary for any assessment report to consider the evidence in relation to each of the three criteria, first separately and then collectively. Details should be provided of the name and version of all standardised assessment measures used, and a brief description should be provided of each of those measures.

### 5.6 Test results and interpretation

The report should provide details of all relevant information derived throughout the assessment process. For each of the three criteria separately, the following should be presented:

- a description of the criterion to be met;
- a summary of the measure(s) used in relation to that criterion;
- the results obtained; and
- a determination as to whether or not the criterion has been met.

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 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.

The psychologist's decision as to whether or not each criterion has been met should be specified, along with an outline of the process that was followed in reaching each determination. This will generally be as detailed above, in Sections 4.2 to 4.4 (and, in the case of severe intellectual disability, Section 4.5). Specifically, the psychologist's opinion as to the person's *true* levels of both intellectual functioning and adaptive behaviour should be presented and discussed. This will involve detailing not just the actual ranges of scores derived throughout the assessment, but also the extent to which the psychologist, using his/her clinical judgement, believes that those scores were impacted by any personal factors that may have come to light throughout the assessment (e.g. the person's mental health and general attitude towards the assessment) or the list of other factors that are known to be possible influences on psychometric test performance identified above (in Section 3). Only exceptionally is it likely that the psychologist's estimate of a true level of functioning will fall outside the reported range of scores. However, the psychologist should always report the reasons for his/her determination in this regard in any event.

Likewise, the psychologist should present his/her decision with regard to an overall diagnosis of intellectual disability: provided *all three criteria* have been met this should be confirmed, otherwise it should not (Section 4.6). However, if either of the two 'impairment' criteria has proven impossible to be determined currently, then, provided none of the criteria has been adjudged to fall outside the intellectual disability range, any formal decision as to whether or not the individual has an intellectual disability should be deferred, pending either the production/availability of additional information or a re-assessment at a later date (generally in at least a further 12 months' time). In the meantime, an interim determination may be made – either that the person has or does not have an intellectual disability – and this may allow for the temporary provision of specialist Intellectual Disability Services, for example. Equally, psychologists should not be reluctant to highlight transient factors that may have depressed a person's scores on one or both assessments, such that he/she may at some time in the future no longer meet the criteria for a diagnosis of intellectual disability.

Once the matter of a possible diagnosis has been dealt with, the report should detail and discuss any significant discrepancies between the person's performances on different subtests of the measures completed.

## **5.7 Summary, diagnostic impression and recommendations**

If the individual is adjudged to have an intellectual disability, the report should focus on the person's specific strengths and weaknesses, with a view to identifying and, where appropriate, making recommendations on both the nature and level of any support needs that are (likely to be) required.

Similarly, if the individual's status with regard to intellectual disability is currently unclear and a decision deferred, the report should identify any specific strengths and weaknesses and indicate both the nature and level of any support needs that are (likely to be) required over the next few months.

If the individual is adjudged not to have an intellectual disability, then whilst there should be no *requirement* for a psychologist (within Intellectual Disability Services) to present a detailed analysis of the person's strengths and weaknesses – other than insofar as they might relate to any other service (e.g. Mental Health Services) to which the psychologist believes the person should be referred – to do so will usually be appropriate.

In any case, an indication should be provided of the response of the person who has just been assessed (and/or, if appropriate, of that person's carers) when informed of the outcome of the assessment and of the recommendations being made.

Finally, an indication should be given of whether a user-friendly version of the current report, specifically for the person who has been assessed, is to be prepared.

## Appendix 1: Intellectual disability and comparable terminology over the years

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The last century has seen a number of terms introduced to refer to the condition that forms the subject of this guidance manual. Within the United Kingdom, these have ranged from ‘mental deficiency’ to ‘mental subnormality’, ‘mental handicap’ and, most recently, ‘learning disability’, whereas in other jurisdictions – most notably the United States – the term ‘mental deficiency’ gave way first to ‘mental retardation’ and then, currently, to ‘intellectual disability’.

Each revision has sought to reflect the current understanding of the condition, while at the same time cancelling the often pejorative associations that have tended to develop over time with whatever terminology has been adopted.

In the United Kingdom, the term ‘learning disability’ was first used officially in 1991. Whilst it has certainly been more socially acceptable than the term which immediately preceded it – ‘mental handicap’ – ‘learning disability’ has unfortunately been prone to confusion with another term, ‘learning difficulty’, which had been introduced a short time previously within the educational sector. (The phrase ‘learning difficulty’ was first adopted in the Education Act 1981, to refer to *any* condition or disability, for example, a profound hearing impairment or dyslexia, which results in a child having a ‘greater difficulty in learning than the majority of children of the same age [and] which prevents or hinders the child from making use of ordinary educational facilities’. This means that a child who has a ‘learning disability’ will by definition also have a ‘learning difficulty’ – but that only a proportion of children who have a ‘learning difficulty’ may be said to have a ‘learning disability’.) The two terms are *not* synonymous. Although they are often used – incorrectly – as though they are referring to the same condition, they are in fact quite distinct.

There is a growing consensus, both nationally (especially in academic circles) and internationally (cf., the latest edition of the ‘definition manual’ of the American Association on Intellectual and Developmental Disabilities – previously the American Association on Mental Retardation) that the term ‘intellectual disability’ should be adopted now as the preferred term.<sup>5</sup> Consequently, the term ‘intellectual disability’ has been used throughout this guidance.

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<sup>5</sup> *Intellectual Disability: Definition, Classification, and Systems of Supports*, 11th Edition (Washington: AAIDD, 2010).

## Appendix 2: The consultation process

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We developed this guidance in response to requests from Faculty members, in recognition that there have been a number of changes in services and legislation since the publication of the Society's previous guidance in 2000 (*Learning Disabilities: Definitions and Contexts*).

We carried out a consultation process, which consisted of workshops, consultation of Faculty members and consideration of reported experiences of the responses of service users to the assessment process. The draft document was sent to a number of people, including some Faculty members who work on clinical training schemes (that is, as well as people who work only in clinical services). We went through a number of drafts on the basis of feedback received.

We held two conferences/workshops in England and Scotland, involving a total of approximately 150 people. The main issues that were raised were: (a) whether we should be using any labels at all for people with intellectual disability; and (b) whether we should use IQ tests as part of the assessment process. There was a range of views on this issue, and the majority view (by a large majority at the workshops) was that diagnosis was required in a large number of situations (including access to services and greater understanding of an individual's strengths and problems), and that formal assessment methods (including IQ testing) were the most reliable and effective method of doing this. This approach is also in accordance with international definitions and approaches to assessment.

We recognised the issues about error at the lower end of scores and, therefore, we have emphasised in this guidance the importance of assessing all three components of the definition of intellectual disability, the use of robust assessment methods and the significance of clinical judgement.

The consultation process also considered how to write reports, and this guidance is included in the document.

Our aim is to provide practical guidance on both assessment and report writing. We think there is a need for psychologists to be transparent about how they come to a conclusion that someone has an intellectual disability, and that they are able to justify their opinions.

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## Notes

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**The British Psychological Society**

St Andrews House, 48 Princess Road East, Leicester LE1 7DR, UK

Tel: 0116 254 9568 Fax 0116 247 0787 Email: [mail@bps.org.uk](mailto:mail@bps.org.uk) Website: [www.bps.org.uk](http://www.bps.org.uk)