

The Identification of an Intellectual Disability, an A to H Framework (IDID A2H[©])

The following alphabetical framework is designed as an aide memoire for the identification of an Intellectual Disability (in children, young people or adults). It will help identify available information sources, gaps in knowledge about an individual's ability and guide decision making regarding a likely diagnosis and generating a needs-based plan. Making a 'diagnosis' of an Intellectual Disability is the remit of psychologists and medically trained professionals. The framework can be used by other professional groups to 'formulate' and gather the appropriate information to establish a likelihood of an Intellectual Disability and guide diagnostic processes or access to appropriate services. It is a longer version of the IDID A2H: short version[®] and the IDID A2H: Parent version[®]

It has been created by the author and is free to use clinically. It can be reproduced for non-commercial uses. Any publication in hard copy or electronically requires permission from the author, <u>Dr Mark Lovell</u>, acknowledgement of the copyright and authorship. No reasonable request will be refused.



Academic

Evidence from education is helpful for understanding an individual's level of functioning. This may be current or predicted attainment or historical information. If in education, it is useful to consider current and past attainment. This may be compared against established expectations for an age group e.g. national curriculum levels. Information may be gained from school or college reports, direct communication with a teacher or results of tests e.g. examinations or specific learning ability tests.

If the person is out of education, it is important to consider how much education was received, whether it was in an appropriate setting and what attainments were made.

Diagnoses may have already been made e.g. of a learning difficulty. Care should be taken to establish whether these are specific e.g. dyslexia or more generalised and what level of difficulty has been assigned. A general rule of thumb is that a generalised moderate to profound and multiple learning difficulty, equates to a mild to profound intellectual disability.

Attendance and engagement in education is also an important factor. Not attending, not engaging, having a specific learning difficulty or behavioural/emotional difficulties that interfere with learning and attainment, or not receiving appropriate education to meet an individual's needs, are likely to contribute to lower attainment irrespective of level of intelligence. It is therefore important to understand the context.

Behaviours of daily living

These are also known as adaptive behaviours or activities of daily living. They reflect a range of skills that are learnt and develop over time. These behaviours include managing personal hygiene, dressing skills, eating, toileting, ambulating, engaging in leisure activities, skills in domestic living to name a few. These behaviours may be assessed in different environments e.g. home and school.

To make a diagnosis of an intellectual disability, evidence of significant delay in adaptive behaviours is required. There are various tests that can contribute towards understanding the degree of delay in adaptive behaviours e.g. ABAS (Pearson website, 2015), ABS (Assessment Psychology Online website, 2001) and Vineland (Pearson website, 2005). Training in the administration of these tests and their interpretation may be required. Direct observation is also important.

Cognitive assessments

Formal assessments of cognition are important in making an accurate diagnosis of an intellectual disability. Formal assessment will calculate a full-scale IQ score and will also produce sub- section scores that describe different areas of skill or difficulty. The IQ score classifies an individual as having an intellectual disability and also gives a reference range of IQ scores that an individual might lie within, with a high degree of certainty.

A variety of IQ tests are available covering different ages or levels of verbal ability. E.g. WIPPSI (Pearson website, 2012), WISC (Pearson website, 2014), WAIS (Pearson website, 2010), or WNV (Pearson website,



2006). These tests are carried out by appropriately trained psychologists. In the UK, Educational Psychologists may also use the BAS (Fountas & Pinnell Literacy website, n.d.).

There are some limitations to cognitive assessments. IQ is supposed to be stable over time however it can worsen if an individual is losing skills or ability e.g. if they have a neurodegenerative condition or if they are choosing or not able to engage with the formal testing e.g. if they are refusing to engage, or deliberately underperforming, if their primary language is not English or if they are not able to communicate or focus.

Short screening IQ tests are available e.g. Ammons and Ammons (Frank & George, 1971) or the KBIT (Pearson Clinical website, 2004); however, they do not produce the level of information that is important to understand an individual's strengths and difficulties. They may be useful for briefly establishing the likelihood of an intellectual disability e.g. by non-psychologists.

Development (other)

Development occurs in a range of areas and at different rates. Physical development includes growth, fine motor, and gross motor and sensory development. Socio- emotional development includes social skills, the development of attachments, play and behaviours. Other areas of development include sleep, speech and language and communication. Investigation and assessment may point towards specific delays or more generalised delays. The degree of these should be considered and needs based plans generated.

There are formal tests to assess these areas e.g. CELF for speech and language (Pearson website, 2013), development scales e.g. Denver and Schedule of Growing skills (GL Assessment website, n.d.) and assessments of behaviours e.g. Adaptive Behaviour Assessment System (Pearson website, 2018) and Adaptive Behaviour Scale (Pearson website, 2005). Some of these can only be carried out by appropriately qualified professionals.

The presence of differing patterns of developmental delay may indicate other conditions e.g. speech, language or communication disorders or other neurodevelopmental disorders.

Environmental Influence

It is important to consider the influences around an individual. This may include understanding the different environments that they live and operate within. The most obvious is the home environment (including the general socio-economic setting) and whether it is supportive of development and learning. In children and young people, school is often the other major influence on development and learning. The therapeutic influence on development of significant time spent in differing settings should also be considered. E.g. if an individual is being neglected and are in an inappropriate educational setting, the likelihood of an individual meeting their academic and developmental potential is less than if they were in an educational setting that did meet their needs.



Factors (other)

Other factors may be present either as a cause of the intellectual disability e.g. genetic conditions or in addition to the intellectual disability. These may either be masked by the intellectual disability or mask the intellectual disability itself. This is called diagnostic overshadowing. Other neurodevelopmental conditions e.g. ADHD or ASD are likely candidates for diagnostic overshadowing.

Mental Health and Behavioural disorders as well as physical health problems are more common in individuals with intellectual disabilities and presentations may be atypical. E.g. tooth ache may present as behaviour that challenges others or a mood disorder may present with more biological symptoms e.g. sleep, appetite or energy level disturbance, rather than clear psychological symptoms. Neurological disorders are common e.g. epilepsy.

Attachment difficulties may also present following early childhood adversity and/or differences in parental responses to a child with a disability. The incidence of abuse and need for safeguarding may also be higher in young people with ID than the general population.

The above factors should be considered holistically, alongside an understanding of the young person's IQ and adaptive behaviours, so that their unique strengths and difficulties and environmental challenges are understood.

General Impression

The 3 main outcomes for use of the IDID A2H $^{\odot}$ are:

- 1) Not an Intellectual Disability i.e. IQ and/or adaptive functioning are within normal range
- 2) Possible Intellectual Disability i.e. further investigation is required over time
- 3) Confirmed Intellectual Disability i.e. IQ is 70 or below and there are significant difficulties with adaptive functioning

It is important to be clear about what terminology is being used and the meaning of this and to communicate this understanding to the individual and involved parties (if appropriate).

The diagnosis may be supplemented by a formulation to understand the factors involved e.g. how is the individual presenting? What has caused or contributed to the diagnosis and what is protective or supportive.

How to meet an individual's needs?

In partnership with the person and their parent/carer, generate a person centred multiagency, multidisciplinary care plan to meet the needs identified in A to G. Plans should include recommendations for the interventions or adaptations required to meet the identified needs (irrespective of the diagnostic outcome). It is important to communicate the findings