The Association
for Child and Adolescent
Mental Health

Factsheet

What is an intellectual disability?

An Intellectual Disability (ID) also known as a Learning Disability is reflective of an IQ below 70 with adaptive behavioural difficulties (daily living skills). This would place an individual's IQ in approximately the bottom 2% of the population i.e. outside of the 'normal' range. There are various classification systems in place. An ID can be classified as mild (IQ 50-69), moderate (IQ 35-49, severe (IQ 20-34) or profound (IQ less than 20).

It is important to know if your child, young person or adult has an ID so that they can be supported in the right way to achieve their full potential. This does not mean that children and adults with an ID cannot live a full life and even gain employment. It is important to have hopes and be aspirational Knowing someone has an ID also may give them legal protection as it is a disability e.g. requirements to make reasonable adjustments and provide accessible information.

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

Parent/carer version

The following alphabetical framework is designed to help parents and carers, alongside professionals, in the identification of an Intellectual Disability (ID) in children, young people or adults. This framework will help identify available information sources, gaps in knowledge about your child, young person or adult's ability and help guide professional decision making regarding a likely diagnosis. It can also help to generate a needs-based care plan to inform appropriate services e.g. health, education and social care.

Other versions of the IDID A2H© framework for professionals are available at www.acamh.org in the Intellectual Disability Topic Guide. Permission to reproduce the IDID A2H© framework, short version or parent/carer version can be gained from Mark.Lovell@NHS.net.

Academic

All individuals with an Intellectual Disability will be delayed academically to some extent. This may mean they have been identified as having additional educational needs. To demonstrate this; gather current, predicted or past attainment information from education. Information may be from school or college reports, a teacher or results of tests or examinations. If out of education, it is important to consider how much education was received, whether it was in an appropriate setting and what progress was made.

Information about an individual's education may need to be provided e.g. attendance, engagement or any factors such as behavioural problems or specific difficulties that interfered with attainment.

Diagnoses may have already been made e.g. specific or generalised learning difficulties. What these are, and their severity is important. Gather and bring along any professional reports.

Behaviours of daily living

These are also known as adaptive behaviours or activities of daily living. They reflect a range of skills that develop over time. An ID requires evidence of significant delays in adaptive behaviours. Tests can contribute towards understanding the degree of delays in adaptive behaviours. Gather any past results and consider the individual's daily living skills and how much support they need e.g. managing hygiene, feeding, toileting, getting around, getting dressed etc.

Cognitive assessments

Formal assessments of cognition by professionals (usually educational or clinical psychologists) are important in the making of an accurate diagnosis of an ID. They produce a full-scale IQ score with sub-sections that cover areas of skill or difficulty. These are required to classify an individual as having an ID and to establish a level of severity.

There are limitations to cognitive assessments. IQ is supposed to be stable over time, however it can worsen if an individual is losing skills or ability, or if they are choosing (or not able) to engage with the testing, or if their main language is not the language that they are being tested in, or if they are not able to communicate or focus.

Gather any past cognitive test results, reports and consider if there are any reasons for under-performing.

Development (other)

Development occurs in a range of areas and at different rates. Physical development includes growth, fine motor, gross motor and sensory. Socio- emotional development includes social skills, the development of attachments, play and behaviours. Other areas of development include sleep, speech, language and communication.

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

Gather and bring any professional reports regarding delays in development e.g. physiotherapy, occupational therapy or speech and language therapy. Consider how the individual developed and whether they met their developmental milestones? Health Visitor or paediatric records may contain important developmental information.

Environmental Influence

The assessment also needs to consider the individual's environment(s) and whether they are or were supportive of development and learning. Were or are there behavioural or other challenges that make this difficult?

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Factors (other)

Other conditions may be masked by the ID, or mask the ID itself. This is called diagnostic overshadowing. Other neurodevelopmental conditions can cause diagnostic overshadowing. E.g. ASD, ADHD. These may need to be considered as part of a wider assessment.

Mental Health and Behavioural disorders as well as physical health problems are more common in people with ID and presentations may not be typical. E.g. pain or physical discomfort may present as challenging behaviour. Do you have any concerns that these might be a factor?

Were there any attachment difficulties following early childhood difficulties and/or differences in parental/carer responses to a child with a disability? Have any safeguarding concerns been raised?

Reasons for an ID may be present e.g. genetics, significant head injury or a condition that affects the development of the brain.

Gather information on any known medical diagnoses and seek an assessment through your local health systems if other factors may be occurring.

General Impression

You are bringing this information to a diagnostic process and assessment. The professional leading this assessment may decide that the individual:

1) **Does Not** have an ID i.e. IQ and/or adaptive functioning are within normal range. Alternative diagnoses or formations should be considered
2) Has a **Possible** ID and further investigation is required over time
3) Has a **Confirmed** ID i.e. IQ is below 70 and there are significant difficulties with adaptive functioning

Please note that the professional leading the assessment might not be qualified to do the tests that help make a diagnosis.

How to meet an individual's needs?

It's important that news about disability is broken sensitively and all involved have the support needed to come to terms with that. It is also important to be positive about the future and to be aspirational for a good and valued life, playing a positive part in society. Professionals in partnership with Parent/carers and the person with ID, should generate a person centred multiagency, multidisciplinary plan to meet the needs identified in A to G. They should communicate the findings and the care plan to the individual's network and work alongside parents/carers to meet an individual's needs e.g. with education, health and social care.

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Key Points

1) Parents and Carers are vital sources of information and may have access to important reports.
2) A structured approach to identifying an ID can assist in making a diagnosis and to consider each person as an individual.
3) Identification requires more than just an IQ score.
4) Alternative diagnoses/formulations should be considered by professionals.
5) Meeting needs is more important than just identifying an ID.
6) Identifying an ID may be required to allow access to specific services

Author

Dr Mark Lovell, Consultant Child and Adolescent Intellectual Disability Psychiatrist,

Tees, Esk and Wear Valleys NHS Foundation Trust

ACAMH Board, Lead for CPD and Training

Chair Child and Adolescent Intellectual Disability Psychiatry Network

Royal College of Psychiatrists Intellectual Disability and Child and Adolescent Faculty executive committees co-opted member