

INTELLECTUAL DISABILITY AND MENTAL CAPACITY ASSESSMENT

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Introduction

Intellectual disability (ID) is a lifelong condition that occurs during an individual's developmental years and can impair decision-making capacity. Other terms that are often used interchangeably include "mental retardation", "mental handicap", "developmental disability" and "learning disability". The preferred terminology as recommended by the World Health Organization is "intellectual disability". The incidence of ID reported in literature varies widely due to the methodological differences in obtaining data. The prevalence of ID is often quoted at around 1% and among those, about 85% have mild ID.¹

Diagnosis

The definition of ID found in the tenth edition of the International Classification of Diseases² and fifth edition of the Diagnostic and Statistical Manual of Mental Disorders^{3,4} are similar. The three essential criteria for diagnosis are the presence of (a) significant impairment in intellectual functioning (eg, reasoning, learning and problem solving); (b) significant impairment in adaptive behaviour (ie, conceptual, social and practical skills in everyday life); and (c) onset before the age of 18 years.⁵

Both intellectual functioning and adaptive behaviours are assessed clinically and may be supported by standardised testing using validated instruments. It involves the assessment of the individual, and interviews with

others such as family members, teachers and caregivers.

Intellectual functioning is often described using the intelligence quotient (IQ) and may be measured using the Wechsler Adult Intelligence Scale, an IQ test designed to measure intelligence and cognitive ability in adults and older adolescents. A full IQ score of 70 and below indicates a significant limitation in intellectual functioning. Intellectual functioning is categorised into the following: mildly impaired (IQ score of 55 to 69), moderately impaired (IQ score of 35 to 49), severely impaired (IQ score of 20 to 34) and profoundly impaired (IQ score of less than 20).⁶

Adaptive behaviour may be measured using various instruments including the Vineland Adaptive Behaviour Scale or the Adaptive Behaviour Assessment System. The three areas of adaptive functioning that are considered are: (a) Conceptual – language, reading, writing, math, reasoning, knowledge and memory; (b) Social – empathy, social judgement, communication skills, the ability to follow rules and the ability to make and keep friendships; and (c) Practical – independence in areas such as personal care, job responsibilities, managing money, recreation and organising school and work tasks.⁷

Generally, an individual with full-scale IQ scores of less than 70 on an individually administered IQ test, accompanied by significant limitation in adaptive functioning in at least two

domains with onset before the age of 18 years, would be considered to have ID.

Aetiology

There are many different causes for the development of ID and they can occur before, during or after birth. Antenatal causes include genetic conditions, infections, exposure to toxins, irradiation and maternal malnutrition. Perinatal causes include asphyxia or hypoxia at birth, mechanical birth trauma, hypoglycaemia and prematurity. Postnatal causes include trauma, anoxia or infections (eg, meningitis and encephalitis) and other environmental factors.⁷

However, in 30% to 50% of people with ID, no cause is found and the aetiology is unknown. This is especially true for those with mild ID. The aetiology is more likely to be identified in those with more severe ID.⁸ In most cases, the cause will almost invariably be multifactorial.

Co-morbidity

Persons with ID experience higher rates of morbidity and mortality.⁹ These co-morbidities may be unrelated or syndrome-specific and part of a behavioural phenotype associated with the underlying aetiology of the ID. Identifying and diagnosing co-morbidities in a person with ID can be challenging due to their underlying cognitive impairments, challenging behaviours and communication difficulties.

Medical conditions commonly seen in persons with ID include visual impairment and eye conditions (23% to 25%), hearing impairment (3% to 24%), dental diseases (11% to 27%), epilepsy (21% to 34%), psychiatric disorders (10% to 14%) and behaviours that challenge (17% to 56%). In addition, they are also at increased risk of chronic medical conditions like hypertension (15.9%), type 2 diabetes mellitus (7.5%) and dyslipidaemia (18%).¹⁰

Persons with ID experience the same range of mental health problems as the general population without ID. Mental health problems are more prevalent in persons with ID and consist of psychiatric disorders and behaviours that challenge. Psychiatric disorders may include psychotic disorders (eg, schizophrenia), affective disorders (eg, major depression and bipolar affective disorder), and anxiety disorders (eg, generalised anxiety disorder, agoraphobia, panic disorder, obsessive compulsive disorder and phobias). The behaviours that challenge may include aggression towards others and self-injury.¹¹

Epidemiological studies have found mental health problems to be present in as high as 40% to 50% of persons with ID, which is significantly higher than that of the general population. The impact on caregiver burden, as well as on the health and social care services, may therefore be considerable.¹²

Communication

People with ID are more likely to be acquiescent, give answers they think is expected of them and be susceptible to leading questions. Closed questions may lead to apparent correct answers when they may not have understood the question at all and may have relied on non-verbal cues (such as tones of voice and facial expressions) to give the response they think the listener is expecting. Open questions may also cause difficulties as they require the individual to think of and then retain a number of possible answers, while simultaneously having to structure their response in a coherent way.¹³

The high prevalence of hearing and visual impairments presents additional communication difficulties. When assessing a person with ID, these

potential barriers to communication should be looked out for and taken into consideration, and reasonable steps should be taken to optimise and improve the person's ability to communicate.

Spectrum of services available for people with ID

In Singapore, home and community support services are available for persons with ID from the early childhood to adulthood stages. For children, there are early intervention programmes and special education schools. For adults, day activity centres, sheltered workshops, vocational training and job support services and residential facilities are available.¹⁴

Mental Capacity Act

The Mental Capacity Act (MCA; Cap 177A, 2010) provides a regulatory framework to address issues related to mental capacity and decision-making.¹⁵ It covers individuals who have an underlying impairment of or a disturbance in the functioning of the mind and/or brain. The code of practice lists stroke, brain injury, dementia, mental health problems and ID as some of the included conditions.

The five statutory principles that underpin the MCA are: (a) a person must be assumed to have capacity unless it is established otherwise; (b) a person is not to be treated as unable to make a decision unless all practicable steps to help him to do so have been taken without success; (c) a person is not to be treated as unable to make a decision merely because he makes an unwise decision; (d) an act done, or a decision made, under this Act for or on behalf of a person who lacks capacity must be done, or made, in his best interests; and (e) before the act is done, or the decision is made, regard must be had to whether the purpose for which it is needed can be as effectively achieved in a way that is less restrictive of the person's rights and freedom of action.

For the purposes of the Act, a person is unable to make a decision for himself if he is unable to (a) understand the information relevant to the decision; (b) retain that information; (c) use or weigh that information as part of the process of making the decision; or (d) communicate

his decision (whether by talking, using sign language or any other means).

Assessment of mental capacity

Doctors may be involved in the assessment of mental capacity for an individual for the purposes of (a) making a Lasting Power of Attorney (LPA); (b) applying for the appointment of deputies by the Court; and (c) in other more specific areas (eg, consent for treatment).

When undertaking an assessment of mental capacity for a particular individual, information and history should be gathered from multiple sources, including interviews with caregivers, in addition to interviewing the person with ID (who should always be involved in the process). It is advisable to have a structured approach in performing the assessment and the use of structured tools will help to facilitate that process. SMA Centre for Medical Ethics and Professionalism (SMA CMEP), in collaboration with the Ministry of Social Family Development, recently developed an online training module and conducted a seminar on "Mental Capacity Assessment for Persons with ID"¹⁶ and has devised a Mental Capacity Assessment Tool, which covers various domains of functioning and can be used by doctors undertaking assessments of mental capacity. For the purposes of applying for an LPA or court-appointed Deputy, the Courts require that Form 224,¹⁷ which comprises both the affidavit and medical report, to be completed. The medical report covers the person's capacity in relation to personal welfare, property and affairs.

It is worth bearing in mind some basic points when undertaking the assessment, namely (a) the presence of ID does not equate to a lack of mental capacity in the person; (b) people with ID have likes, dislikes, preferences, choices, skills and talents, and these should be asked for; (c) physical appearances should not prejudice any mental capacity assessment (eg, for someone with features of Down syndrome); (d) institutionalisation or living in residential homes does not equate to a lack of decision-making capacity; (e) a person with ID has limited life experiences which may limit their ability to understand situations or information provided; (f) traditional IQ tests segregate individuals

and should not be the only method of assessment; and (g) there may be biases inherent in the society's and family's perception of people with ID.

In practice, when carrying out the assessment, the assessor should (a) be patient and be prepared to listen; (b) be able to establish rapport with the caregiver and the person with ID; (c) be aware of any sensory impairments in the person with ID which may affect the assessment process; (d) seek the most accurate and up-to-date information

from the informant or caregiver; (e) expect that medical records are not always available and that very limited healthcare information may be available at the time of the assessment; and (f) follow a structured approach and consider using a standard tool or questionnaire.

In summary, people with ID have complex health and social care needs, and may lack mental capacity to make specific decisions. Doctors undertaking an assessment of mental capacity for

this group of patients need to bear in mind the requirements under the Mental Capacity Act, be aware of and address potential barriers to an effective assessment and apply good practice guidelines to ensure that they perform the assessment to a reasonable standard.

The next SMA CMEP seminar on Mental Capacity Assessment for PWIDs will be held in April 2018. Do look out for it. ♦



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