Communicating with people with intellectual disability (ID)

A resource prepared by the Intermediary Pilot Program

Background and Overview

Intellectual disability

Intellectual disability (ID) is a life-long neurodevelopmental disorder that is defined by significant cognitive deficits in the areas of reasoning, problem solving, planning, abstract thinking, judgement, academic learning and learning from experience.

Intellectual impairment is made more complex by a high incidence of comorbidity, so it is highly likely that someone may have more than one area of cognitive impairment (i.e. ID and mental illness). There is a higher incidence of people with ID having a genetic syndrome (i.e. Down Syndrome and Fragile X Syndrome), physical health difficulties (i.e. epilepsy, cerebral palsy, neurological impairment) and sensory problems (i.e. hearing and visual impairment, sensory processing dysfunctions).

ID affects approximately 1.86% of the total population in Australia.[i] Although prevalence estimates vary, as many or more than 40% of people with an ID also have a mental illness, followed by a comorbid physical disability (40%) and over 30% also have a speech related difficulty. Common comorbid psychiatric disorders found in people with an ID typically include problem behaviours (18.7%), affective disorders (5.7%: i.e. depression, bipolar disorder), Autism Spectrum Disorder (ASD) (4.4%), psychotic disorders (3.8%; i.e. schizophrenia, schizoaffective disorder) and anxiety disorders (3.1%; i.e. generalised anxiety, panic disorder, post-traumatic stress disorder).[ii] There are also significantly higher rates of Attention Deficit Hyperactivity Disorder (ADHD) among people with ID.

Definition of intellectual disability

The *Disability Act 2006* (Vic) defines intellectual disability as the concurrent existence of:

a) significant sub-average general intellectual functioning; and
b) significant deficits in adaptive behaviour.

In addition, the person must be aged over 5 years and both deficits must have become evident before they were aged 18.

Sub-average general functioning is defined as a full-scale intelligence quotient (FSIQ) on a standardised cognitive assessment of under 70 (FSIQ<70). Significant deficits in adaptive behaviour means deficits in two or more adaptive behaviours (like daily living skills, socialisation, motor skills and/or communication) that affect every day, general living.

The FSIQ is a measure of someone's general intellectual ability, made up of scores from subtests that measure specific cognitive areas such as verbal comprehension, perceptual, working memory, and processing speed. An individual's intelligence score can be reported in terms of how they function compared to same-aged peers in the general population (e.g. FSIQ may indicate they function at the 50th percentile for same aged peers). They can also be reported as a range of scores within which the true score of the individual is likely to fall (e.g. their true FSIQ falls somewhere between a score of 55 and 66). It is very common for an individual to have score differences across all the cognitive areas assessed. For example, someone with an ID may have a relative skill in working memory but very poor verbal comprehension, even though both skills make up the verbal IQ subtest.

There are four main definitions of ID that are categorised according to the FSIQ: mild, moderate, severe, and profound. The ID categories cover a very broad range of presentations, individual skills and difficulties. Most people with an ID (85%) have a mild disability, followed by a moderate (10%), severe (3-4%) and profound (1-2%) disability.[iii] Most people giving evidence will have a mild to moderate ID.

Current best practice tries to focus more on an individual's daily skills than on specific IQ ranges. For example, those with a mild ID are generally likely to be more independent and require less intensive communication support than those with lower levels of intelligence. It is always important to try to understand an individual's personal strengths, difficulties, and subsequent communication support needs. If an Intermediary is not involved, consideration may need to be given to accessing relevant information from a range of alternative sources (e.g. family, support services).

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Common Issues

Generally, people with an ID have differing degrees of difficulties within three adaptive functioning domains: conceptual skills (language, knowledge and memory), social skills (empathy, social judgement and rule-following ability) and practical skills (self-care, organisation and daily living skills).[iv] [v] [vi] [vii]

Conceptual Skills

- May have difficulty with complex language-based concepts
- Limited vocabulary and conceptual development can lead to overgeneralising meanings and a lack of ability to give specific descriptions
- Making causal inference
- Difficulties with suggestibility
- They may agree with suggestions (acquiesce) to complete the interaction, whether they have understood the question or not
- Difficulty understanding abstract concepts and complex instructions (i.e. compound questions)
- They may be unable to refute incorrect assertions or ask for more time to think
- May present as socially skilled but have difficulties with language-based concepts, both in understanding (receptive language) and use of rote responses (expressive language)
- The need for alternative or augmented communication (AAC) such as key word sign and gesture or picture-based communication systems
- Literal and concrete interpretation of higher-level language
- Low literacy levels (i.e. reading and writing)
- Specific learning difficulties
- Difficulties concentrating and processing information.

Social Skills

- Difficulties with insight and judgement.
- Difficulties with generalisation of concepts and skills across environments.
- Non-verbal reasoning (i.e. picture sequencing).
- Difficulties dealing with stress and anxiety related to unfamiliar people and new environments.
- Poor understanding of the motivations or perspectives of others.
- Poor social skills.
- Difficulties managing emotions and impulse control.

Practical Skills

- Organising daily activities.
- Time keeping and attending scheduled appointments.
- Requiring additional supports to engage in social activities, community living and/or attend to aspects of their self-care (i.e. safety and health).

Case Example: Annie

Annie is a 17-year-old with a diagnosis of Down Syndrome. She lives in supported accommodation and requires supports with most areas of domestic and community living. She is diagnosed with a moderate intellectual disability with a FSIQ of 46.*

Annie communicates verbally, although her speech is unclear and only understood easily by those who know her well. She has good social skills that enable her to participate in everyday social interactions. She uses a communication board with pictures and symbols.

Annie presents with difficulty understanding vocabulary and language concepts outside of her everyday experiences. She also has difficulty with vocabulary and the use of a communication board can assist her with unfamiliar words or concepts.

Annie may agree with questions put to her if she does not understand. It is better to ask her a question that requires narrative rather than 'yes'/'no' responses. She does not have insight into her own difficulty understanding, or the degree of difficulty others have in understanding her.

Strategies

The information below outlines general strategies that can be adopted by representatives of the court to enhance communication with people diagnosed with an intellectual disability.

- Provide more time to process language and respond
- Keep questions and instructions short and direct
- Ask one simple question at a time and avoid questions with multiple parts
- Use simple questions that start with 'who', 'what', 'when' or 'where'
- Avoid the use of 'why' or 'how' questions
- Ensure questions are phrased simply (avoid hypothetical, tag, leading or negative questions)
- Make it clear when you are changing topics. Visual topic indicators can also assist
- Ask questions in a logical and sequential order and signpost the start and end of conversation topics
- Use a combination of verbal and visual information suited to the person's needs
- Say what you mean. Avoid figures of speech
- Monitor stress, anxiety and fatigue. Schedule regular breaks as required
- Use everyday language and personally meaningful language
- Ask questions that require an answer rather than just no/yes or forced choice questions
- For people with a moderate ID consider the use of existing AAC aids or developing them as required
- Do not use IQ scores alone to determine an individual's strengths and weaknesses.
- Consider the impact of other co-morbidities (i.e. mental health, sensory regulation) in influencing their communicative ability

Case Example: Stacey

Stacey is a 43-year-old woman with a mild ID (FSIQ = 66). She has specific difficulties with delayed memory recall with her skills being in the first percentile compared to peers of her age in the general population. She has a diagnosis of Borderline Personality Disorder (BPD) and is supported by her local area mental health service. She has pharmacological treatment to assist her with regulating her emotions and to assist her with sleeping (she suffers nightmares from previous traumas). She lives independently with some outreach type service supports. She has difficulty engaging with people who she does not know well and experiences increasing levels of stress and anxiety in relation to unfamiliar environments. At times of increasing stress and anxiety she engages in self harming behaviours.*

Stacey finds it easier to respond when questions are asked via a well-known support person. She has difficulties managing her emotions and speaks in a loud manner. She can maintain attention for short periods before she requires a break to assist with emotional regulation. She does not maintain eye contact, often appearing disengaged, despite still actively listening to the conversation. Stacey responds to clear expectations around what is expected of her (e.g. using a visual schedule). She has good visual memory skills. Stacey has basic reading and writing skills.

References

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