

Fact sheet

For clinical and non-clinical professionals
who work with young people

Intellectual disability and youth mental health

Intellectual disability (ID) is the term given to permanent impairment in general mental abilities, which results in reduced functioning. It is a lifelong disability with onset during the developmental period, typically before 18 years of age. ID is diagnosed following standardised testing and assessment of cognitive and adaptive functioning relative to same-aged peers.

ID impacts on conceptual (e.g. language, knowledge and reasoning), social and practical skills, and can range from mild to severe. People with an ID have a wide range of support needs depending on their level of disability.

Orygen has prepared this fact sheet in collaboration with Professor Julian Trollor, Dr Janelle Weise and the team at the Department of Developmental Disability Neuropsychiatry, University of New South Wales.

Co-occurring mental illness and intellectual disability in young people

Young people with ID experience the same range of mental illnesses as those in the general population – including depression, anxiety and psychosis – but at a higher rate. People with ID are 4.5 times more likely to experience mental illnesses than those in the general population. The more severe the ID, the greater the vulnerability to mental illness. This is because people with an ID are more likely to experience things that are risk factors for mental illness (e.g. biological factors, physical health issues, stigma and discrimination, lack of financial and other resources) and less likely to experience protective factors.

As people with ID are a very heterogeneous group with a wide variation in communication skills and functioning, mental ill-health can manifest in unique ways, making it hard to recognise. Mental ill-health often goes unrecognised and untreated, with behavioural changes misattributed to ID.

When a person with ID or their support network identify that there may be an underlying mental illness, they are likely to experience a number of barriers when they attempt to seek medical help and treatment. These include, for example, communication difficulties, lack of specialised services for people with an ID, mental health professionals who lack knowledge, skills and confidence in the area of intellectual disability mental health, carers and disability professionals who also lack knowledge, skills and confidence in the area of intellectual disability mental health, and poor communication between services involved in supporting the person (e.g. disability services, community services, primary care, etc.)

Assessment and treatment of mental illness in young people with intellectual disability

A careful and detailed assessment – including history, baseline functioning, and current symptoms – is required in order to diagnose mental illness in those with ID, and it may be important to use multiple sources of information. Similarly, special care and adaptation of mental health treatments is required in order to meet the needs of young people with comorbid ID and mental illness.

Young people with ID can benefit from the full range of mental health treatments that are available, but these must be applied with care to ensure that their specific needs are upheld. A shortage of research on mental illness in people with ID means that specific guidance on adapting treatments for those with ID may be lacking and evidence-based practices from the general population must be carefully trialled and monitored.

Issues in pharmacological treatment

People with ID often experience both communication difficulties and physical comorbidities, which can complicate medication use, so clinicians need to monitor these carefully and be vigilant about medication interactions.

Polypharmacy and medication sensitivity

It is well known that people with ID can be more sensitive to medications, require lower doses, experience more severe side effects and have idiosyncratic reactions. It is also common for people with ID to experience polypharmacy, whereby multiple medications are prescribed and their interactions have not been carefully considered.

Medication management

Good medication management for young people with ID requires careful assessment and a holistic, co-ordinated approach in which a good rationale for all medications is developed, effects are carefully monitored and systematically reviewed, and a ‘start low and go slow’ ethos is applied. Close collaboration, communication and coordination between all health professionals involved in the young person’s care is required to ensure that medication use is carefully managed.

Issues in psychosocial treatment

Psychological therapies – such as behavioural therapy, cognitive-behavioural therapy (CBT), dialectical behaviour therapy (DBT), family therapy, acceptance and commitment therapy (ACT), and general counselling – can be helpful for mental health issues in young people with ID.

Depending on the communication and functioning level of the young person, clinicians need to adapt therapeutic techniques to make them accessible to people with ID. Adaptations to psychosocial treatments include:

- using simplified language and concepts
- going at a slower pace
- using pictures and other non-verbal methods to enhance communication
- using concrete examples.

Communication style

People with ID commonly experience problems with communication, which can include impairments in their expressive and receptive communication skills. Communication skills differ from person to person and the severity of an ID can impact these skills. Some people with ID may use a range of techniques or technologies (e.g. type and talk devices) to supplement or replace their speech or writing; this is also known as augmentative and alternative communication (ACC). Careful attention to the preferred communication style of the young person and any adaptations or aids they prefer is essential to providing good clinical care.

Engagement

Engagement of a young person with ID in psychological therapy may require greater flexibility with timing and location of sessions, and working creatively with others who know the young person well to find what works best for each young person.

Regularly checking that the young person understands discussions and suggestions is important, and asking them to summarise messages is a good way to gauge this. It may also be appropriate for clinicians to be more directive in therapy with young people with ID than they may be in other situations. However, clinicians must ensure that they have obtained appropriate informed consent from their young person for all treatment provided.

Lifestyle interventions

Lifestyle interventions that encompass diet, sleep, exercise, daily routines and reducing substance use are important components of mental health and are relevant and effective for people with ID and mental ill-health. Poor diet, social isolation, and physical inactivity are often issues for those with ID, and mean that interventions to address these factors need to form part of treatment goals and plans.

Similarly, improving social connectedness and increasing enjoyable activities to build self-esteem, coping and resilience all contribute to mental health and quality of life, and are important components of holistic healthcare for people with ID. As with psychological therapy, lifestyle and social changes need to be carefully designed and implemented for those with ID to overcome communication difficulties, physical health challenges and financial disadvantage.

Further information

3DN (Department of Developmental Disability Neuropsychiatry, University of New South Wales) – resources for professionals and carers, online training.

Centre for Developmental Disability Health (CDDH) – resources and training to support health services to address the health needs of adults with intellectual disabilities.

Queensland Centre for Intellectual and Developmental Disability (QCIDD) – education, information and resources.

Apps and tools for people with disabilities (Queensland Government).

Victorian Dual Disability Service – a joint mental health initiative between St Vincent's Hospital Melbourne and Melbourne Health to provide a consultation service for Victorian mental health services and online training.

Carer Gateway (Australian Government) – information and support groups for carers of someone with an ID.

New South Wales Council for Intellectual Disability – a disability rights organisation led by people with intellectual disability.

The New South Wales Agency for Clinical Innovation – resources related to the care and health of people with ID.

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