



An introduction to Depression in People with an Intellectual Disability

Never Stand Still

Medicine

Department of Developmental Disability Neuropsychiatry



Associate Professor Julian Trollor
Chair, Intellectual Disability Mental Health
Head, 3DN
School of Psychiatry, UNSW
j.trollor@unsw.edu.au

Main Points

- The goal
- Mental ill health in people with an Intellectual Disability
- Why are people with ID at risk?
- Barriers to access to good quality mental health care
- Similarities and differences in presentation of mental health problems in people with ID
- Approach to Diagnosis
- Approach to management
- Resources
- Cases
- Questions

The Goal

- The highest attainable mental health and well being for all people with an intellectual disability

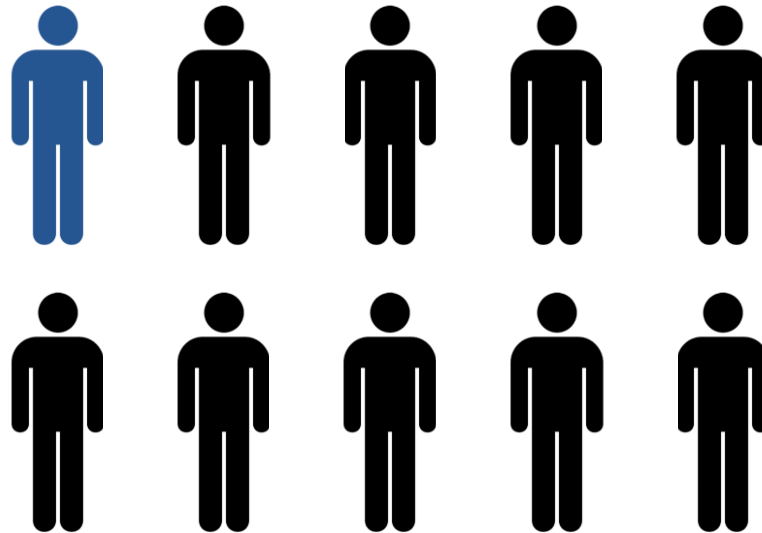
Why this topic?

- About 2% of the population have an intellectual disability
- Mental health problems are common in people with an ID
- Community-based studies of epilepsy in adults with an ID show a prevalence of 16–26%
- A person with both an ID and epilepsy has greater vulnerability to mental ill health

- I would be happy to give a further webinar on the relationship between epilepsy and depression

How Common are Mental Health Problems? General Population

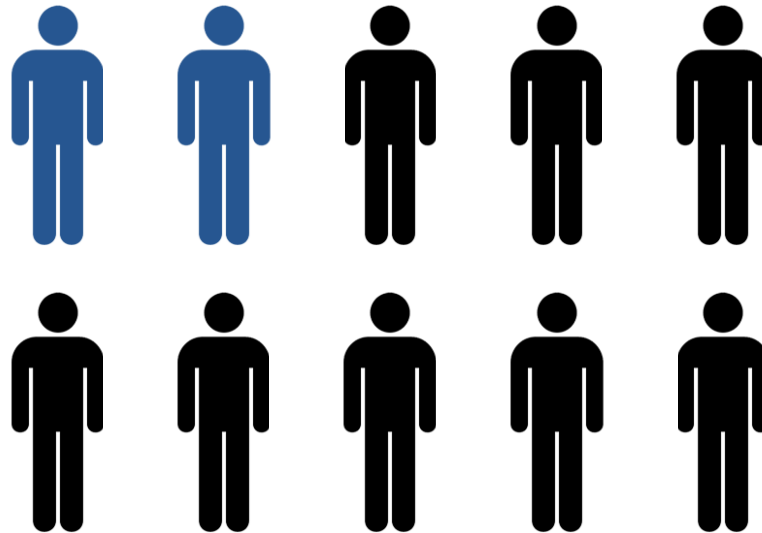
- About 1 in 10 people in a month (NB survey excluded people with an ID)



2007 National Survey of Mental Health and Wellbeing

How Common are Mental Health Problems? General Population

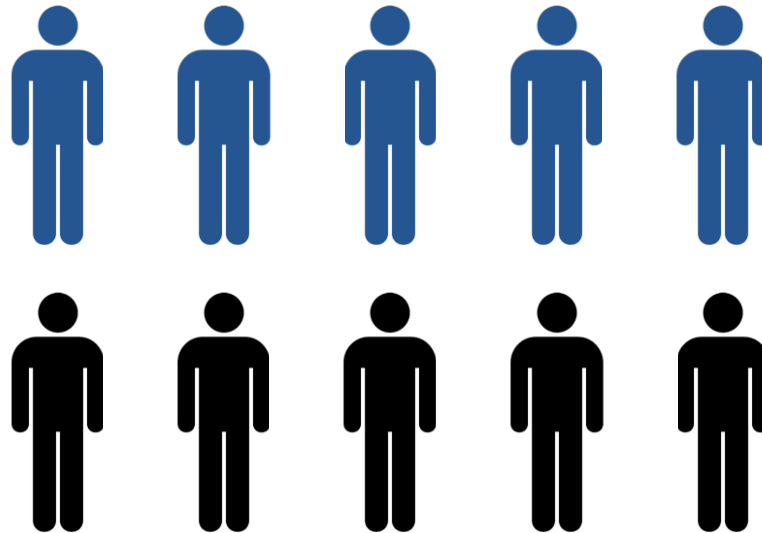
- About 2 in 10 people in a year



2007 National Survey of Mental Health and Wellbeing

How Common are Mental Health Problems? For people with ID

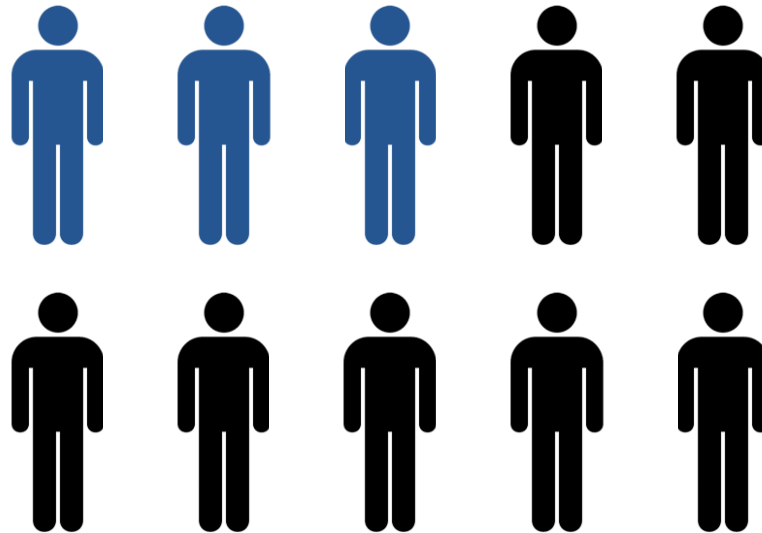
- About 4 or 5 out of every 10 people in a year



Cooper et. al., 2007

How Common are Mental Health Problems? For carers

- About 3 out of every 10 people in a year



Savage and Bailey, 2004

Mental Health of People with an ID

- People with an intellectual disability experience an over-representation of mental disorders
- Access to mental health supports and treatments is limited
- High impact for people with ID, families and carers
- Complexity
- Multiple vulnerabilities



ID Mental Health across the Lifespan

- predisposition to mental ill health across the lifespan
 - Children: neurodevelopmental disorders
 - Younger persons: Schizophrenia over-represented 2-4 x, earlier onset in people with an ID.
 - Older persons: higher rates of dementia.

Prevalence of Mental Disorders in Adults with ID (Cont)

- General Population:
 - 2007 National Survey of Mental Health and Wellbeing: 20% of general population experience some form of mental disorder in past 6 months
- People with ID:
 - Prevalence estimates vary – differing definitions and methodologies
 - Estimates from 7% to 97% (Cooper et al., 2007)
 - A conservative estimate for adults with ID = ~2.5 x higher

Poorer access to treatments

- Low rate of treatment & often unknown to mental health services
 - Only 10% of adults with ID and psychopathology received mental health interventions across a 14 year period (Einfeld et al., 2006)
 - cf. 34.9% of people with a mental disorder accessed mental health services within a 12 month period (Slade et al., 2009)
- Reasons?
 - Families & care staff untrained in mental health, unable to recognise indicators
 - Inadequate mental health professional training in ID
 - Diagnostic difficulties
 - Until recently there has been little research on the use of psychological therapies other than behavioural treatments for people with ID (Emerson & Holland, 1997)

Access to MH Services and Supports



Vulnerabilities to Mental Illness in ID

Social risk factors

- Social isolation
- Social adversity
- Adverse life events
- Stigma
- Communication difficulties
- Reduced social skills
- Absence of family support

Biological risk factors

- Physical inactivity
- Poor diet
- Multiple health conditions
- Polypharmacy
- Epilepsy
- Head injuries
- Family history of mental disorder
- Genetic anomalies – eg Velocardiofacial syndrome is associated with higher rates of mental disorder, particularly schizophrenia

Various combinations of social, psychological or biological risk factors

- Social and communication impairments, eg those associated with autistic disorder
- Family stress or conflict
- Interpersonal difficulties
- Chronic pain
- Atypical physical appearance
- Motor impairment
- Lower IQ
- History of trauma and abuse
- Experiences of loss, grief, or unwanted life changes
- Being easily manipulated
- Deprivation or neglect
- Below average achievement

Psychological risk factors

- Maladaptive coping strategies
- Feeling overwhelmed
- Stress and anxiety
- Low self-esteem
- Emotional lability
- Capacity for self-harm

Risk Factors for Depression in Epilepsy

Psychosocial	Low income and unemployment Negative Attributional style Lower sense of self efficacy and problem solving
Demographic	Family history of affective disorder
Seizure-related	Left-hemisphere focus Temporal lobe epilepsy/Complex partial seizures Absence of secondary generalized tonic clonic seizures Treatment resistance
Treatment Related	Polypharmacy Certain AEDs eg phenobarbital, primidone, phenytoin, vigabatrin, topiramate Folate deficiency Temporal lobectomy
Other	Neurological disorder Frontal lobe dysfunction

Profile of Mental Disorders Varies with Severity of ID

- Rates of specific disorders varies according to severity of ID
 - prevalence increases with increasing disability
 - psychopathology varies with increasing disability

Profile of Mental Disorders Varies with Severity of ID (Cont)

- Mild-moderate ID: full spectrum of mental disorders
- Moderate-severe ID: different symptom profile, discrete Sx difficult to identify
 - Behavioural analysis and 3rd party reports rather than self-reported Sx
 - Severe mental illness can sometimes be identified
 - 15-50% stereotyped behaviours
 - 10-20% self injurious behaviours

Presentation of Mental Disorders in Adults with ID – Reminder

- A mental disorder can affect mood, thoughts, behaviour, arousal, and social, interpersonal and physical functioning
- Presentations of mental disorders can include
 - subjective changes such as feelings of guilt, anxiety, auditory hallucinations, persecutory ideation, etc
 - changes that are readily observable by others such as changes in sleeping, appetite, weight, talkativeness, agitation, irritability, sociability, aggression, self-injurious behaviour etc

Presentation

- Adults with mild ID and/or reasonable verbal skills: ***similar presentation to adults without ID***
- Adults with moderate-severe ID, ID & autism, or limited verbal skills: ***↑ changes in behaviour, including disturbed or regressed behaviour***

Presentation – ambiguities

- Changes that seem to indicate a mental disorder may have other causes, eg
 - medication side-effects, pain, or physical illness/disorder
 - bizarre behaviour in response to a stressor, or disorganised speech, giggling and silliness may be an idiosyncratic feature of the disability rather than signs of psychosis

Presentation – ambiguities

- Changes due to a mental disorder may be incorrectly perceived as normal in the context of the ID, eg
 - grandiosity may be mundane, such as imitating a staff member
 - withdrawal and decline in social skills due to psychosis are incorrectly ascribed to the ID
 - onset of a new disorder is missed, due to pre-existing high levels of unusual behaviours

Presentation – activity

- Typical criteria for mental disorders (eg DSM) rely heavily on self report of symptoms, or interpretation of complex verbal output
- Self report and comprehensive language may not be available in people with ID
- Brainstorm the creation of operational observable diagnostic criteria for a depressive episode for adults with a mild-moderate intellectual disability

Criteria for Depression & Mania

Depression	DSM-IV	ICD-10
Depressed mood, most of day, most days	✓	✓
Loss of interest/loss of pleasure	✓	✓
Significant weight loss	✓	✓
Insomnia/hypersomnia/sleep disturbance	✓	✓
Psychomotor agitation/retardation	✓	✓
Fatigue/loss of energy	✓	✓
Feelings of worthlessness, guilt, self reproach	✓	✓
Diminished ability to think, concentrate, decide	✓	✓
Recurrent thoughts of death, suicide	✓	✓
Loss of confidence/self esteem		✓

Your Turn

Specific Criteria for mental disorders in people with ID?

- DM-ID (DSM 4, 5 coming)
- DC-LD Criteria

Eg DC-LD for Depression

E: Item 1 or 2 must be present and prominent:

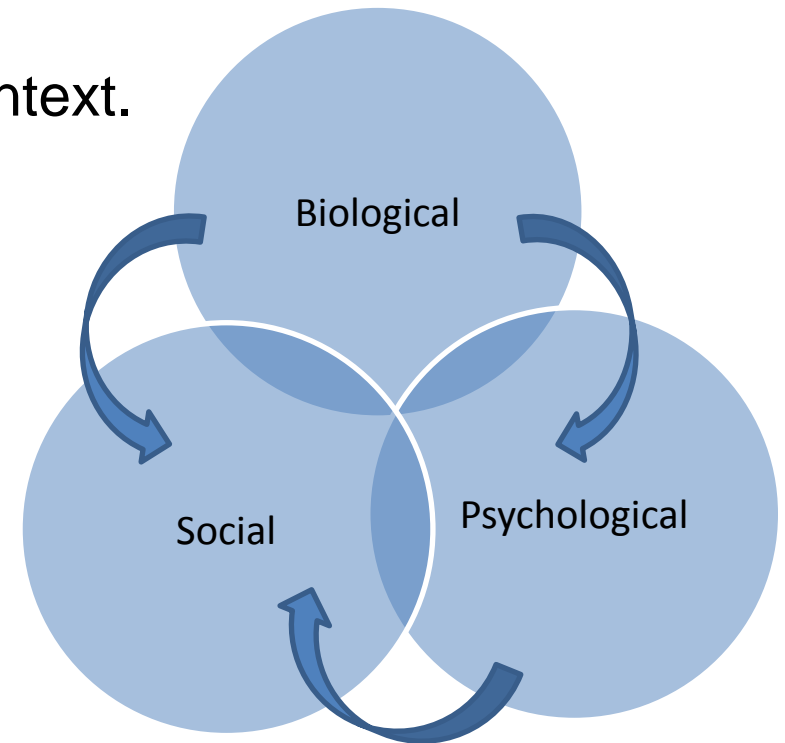
1. Depressed mood (misery; failure to maintain usual mood state throughout the day)
or irritable mood (includes onset of or increase in aggression; reduced level of tolerance)
2. Loss of interest or pleasure in activities
or social withdrawal
or reduction in self care
or reduction in the quantity of speech/communication

F: Some of the following must be present so that at least four symptoms from E and F are present in total

1. Loss of energy; increased lethargy
2. Loss of confidence *or increase in reassurance seeking behaviour/ onset of or increase in anxiety or fearfulness*
3. Increased tearfulness
4. Onset of or increase in somatic symptoms
5. Reduced ability to concentrate/distractibility *or increased indecisiveness*
6. Increase in a specific problem behaviour
7. Increased motor agitation *or increased motor retardation*
8. Onset of or increase in appetite disturbance *or significant weight change*
9. Onset of or increase in sleep disturbance

Approaches to treatment in people with ID

- Management of mental illness in people with intellectual disability (ID) follows similar principles to the general population.
- Depends on severity/treatment context.
- Biopsychosocial approach:
 - Psychological interventions
 - Pharmacological interventions
 - Social support



Engaging carers

- Engaging carers and family members in the assessment and management, including monitoring and reporting treatment progress or adverse events is particularly important when a person has ID.
- The involvement of carers (paid and non-paid)
 - engages the support person in the therapeutic process
 - allows the carer to promote continual reinforcement of information provided in treatment or therapy.

Mental Health Promotion and Relapse Prevention

- Just as important for adults with ID as it is for their non-ID peers
- Promotion
 - Lifestyle, exercise, addressing vulnerabilities
- Early intervention
 - depression, bipolar disorder, schizophrenia

Treatment of Common Mental Disorders in ID-I

	Health Professionals Involved			Treatments
	GP	Psychiatrist	Psychologist	
Depression	✓	✓		Anti-depressants Antipsychotics ECT
	✓	✓	✓	CBT Counselling
Bipolar	✓	✓✓		Mood stabilisers Antipsychotics Antidepressants ECT
	✓	✓	✓	Counselling -adjunct

Treatment of Common Mental Disorders in ID- II

	Health Professionals Involved			Treatments
	GP	Psychiatrist	Psychologist	
Anxiety Disorders	✓	✓		Anti-depressants Anxiolytics (Short-term)
	✓	✓	✓	CBT
Schizophrenia and Related Disorders	✓	✓✓		Antipsychotics +/- other
	✓	✓	✓	Counselling -adjunct

Prevention

- Increased opportunities for choice and independence
- Skill building & promoting resilience
 - teaching coping strategies, problem solving, relaxation strategies, communication skills
 - developing a support system e.g. who to talk to about problems/issues

Prevention cont...

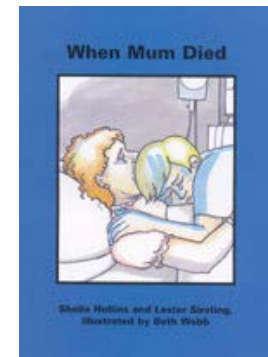
- Increased activity
 - reducing boredom & increasing opportunities to feel a sense of achievement & purpose – via day programs, social groups, sports or hobbies, community college courses, etc
- Environmental modifications
 - family/staff training in mental health, early warning signs, and how to provide a supportive, validating environment
 - changes to light/noise/space

Depression

- Depression is under-recognised and under-treated in people with ID.
- Specific management principles for people with ID:
 - evaluation of environmental triggers
 - Hierarchical approach based on severity/duration of symptoms
- Seek specialist psychiatric opinion when the person:
 - has suicidal ideation/attempted suicide
 - has psychotic symptoms
 - is at risk from self neglect/inadequate oral intake
 - does not respond to treatment
 - has a manic episode triggered by treatment

Psychological interventions

- Psychotherapies: first-line management for mild anxiety and depressive disorders in people with ID.
- Psychological interventions can be modified
- for people with ID by:
 - simplifying concepts
 - taking longer to establish rapport
 - repeating the presentation of material
 - using pictures and other aids
 - (e.g. Books Beyond Words)
 - enhancing the behaviour aspects of the therapy
 - engaging a support person/family member



Pharmacological interventions

- Psychopharmacological interventions commonly used
- Prevalence of use:
 - 20-50% on psychotropic medications [Clarke 1990, Deb 1994, Branford 1994, Holden 2004, Tsiouris 2010]
- High prescription in some groups:
 - 48% of those with challenging behaviour [Kiernan 1995]
- Antipsychotics - most widely prescribed medications in people with ID (Tsiouris 2010)

Pharmacological interventions: problems

- Discrete psychiatric disorders can be hard to identify in some people with ID
- Relative absence of evidence on efficacy [Brylewski 2004, Tyrer 2008]
- Inadequate definition of, and variable approach to challenging behaviour
- Sensitivity to side effects
- Potential for complication of other medical disorder
- Can worsen behaviour in some individuals

Principles of pharmacological treatment

- Principles of prescribing and treatment are generally the same for people without ID
- Dependent on
 - diagnosis
 - symptoms
 - duration and severity
 - risk
 - side effect profile
 - previous responses to treatment
- HOWEVER....

Prescribing can be more complex

- Sensitivity to side effects:
 - Side effects may be more frequent, more intense, and more idiosyncratic in those with ID compared to those without ID
- Some medications worsen pre-existing conditions
 - eg swallowing difficulties, epilepsy, reflux, constipation etc
- Monitoring actively for side effects is important
 - How might someone with an ID communicate side effects, particularly in the context of communication difficulties?
 - How might side effects in someone with an ID be monitored?
 - Correct attribution eg agitation can be a side effect or due to an underlying mental disorder

Prescribing can be more complex

- The importance of an accurate diagnosis – if the diagnosis used to guide prescribing is incorrect, the medication is less likely to work
- Possible atypical response to medication
- Higher risk of polypharmacy
- May require active monitoring of side-effects
- May require support to manage compliance
 - involving carers
 - simplifying instructions and interventions
 - depends on individual circumstance

Common errors in prescribing

- Lack of clarity and consensus in prescribing practices
 - Antipsychotics are the most common class of medication prescribed to adults with ID, however often with no clearly documented rationale
 - Use of “older” versions of medication that have more side effects
 - Overdosing, leading to sedation
 - Under- and over-prescribing
 - Polypharmacy

Common errors in prescribing

- No review mechanisms
 - Medications continued despite no change in signs/symptoms
 - Extended use of crisis medications
- Use as a substitute for non-medical therapies
- Medications used to suppress “reasonable” emotions/behaviour, such as grief
- Poor self-advocacy = carers’ and clinicians’ response to toxicities/side effects may be delayed

Principles of use

- Before prescribing psychotropic drugs, mental and physical health should be comprehensively assessed to:
 - screen for any underlying medical causes of psychiatric symptoms
 - identify any underlying medical conditions that may impact on treatment
 - provide a baseline for evaluating effectiveness of treatment.
- Only use psychotropic drugs as part of a comprehensive mental health care plan that addresses broader psychosocial concerns and physical comorbidities.
- Obtain consent.

Selection and commencement of drug therapy

- The impact of medical comorbidities should be considered when selecting a psychotropic drug
 - e.g. for a person with obesity and type 2 diabetes avoid drugs that stimulate appetite
- Define what symptoms you are targeting and develop clear, predefined and reliable methods to monitor treatment response
 - E.g. Daily chart of number of incidents of a specified type
- Commence psychotropic drugs at a low dose, and increase gradually
 - “start low and go slow”

During therapy

- Engage support people in monitoring and reporting benefits of treatment adverse effects
- Regular reviews of:
 - Adherence to therapy
 - Treatment progress
 - Adverse effects
 - need for continuing the drug
- Withdraw a psychotropic drug if it:
 - Is not effective
 - Has intolerable adverse effects
 - Is no longer required

Optimal prescribing

- Biopsychosocial assessment
- Monitor physical health
- “trial” as opposed to “commencement”
- Start at lower doses
- Ongoing review of benefits and side effects
- Collaborate with consumers and carers
 - Educate about adverse reactions and side effects
- If treatment is ineffective, reconsider diagnosis
- Multidisciplinary decision making
- Use medication as an adjunct to other interventions

Precautions in prescribing psychotropics

- Adverse effects more likely in people with ID
- Physical comorbidities can increase likelihood of sensitivity
 - Eg potential to lower seizure threshold/increase risk of seizures
 - Sedation = increased risk of respiratory complications/aspiration/dysphagia in some conditions.
- People with ID may have increased sensitivity to cognitive effects of drugs (particularly older adults with conditions linked to increased risk of dementia)
- Impaired cognitive and communication skills means people with ID may not recognise/report adverse effects of drugs – may be manifested as behavioural change.

Discontinuing treatment

- Reasons for discontinuing psychotropic drugs:
 - Lack of clear indication for prescription
 - Condition resolves
 - Complications develop (e.g. Severe tardive dyskinesia)
- Withdrawal from long-term antipsychotic therapy is more likely to be difficult when the person:
 - is taking high doses of the drug
 - has a high baseline of challenging behaviour.
- Effects of withdrawal can be:
 - temporary exacerbation of behavioural difficulties
 - withdrawal dyskinesias

Adverse effects

- People with ID have potential sensitivity to adverse effects and higher rates of comorbid medical conditions.
- People with developmental disability may not be able to communicate the experience of adverse effects. Behavioural change (e.g. Increased aggression, self-injury or repetitive behaviour) can be:
 - a manifestation of discomfort or distress associated with an adverse effect of a drug
 - a direct behavioural effect of the drug.

Electroconvulsive therapy (ECT)

- ECT may be indicated in people with ID who are severely depressed and have other complexities (e.g. psychotic features/poor response to antidepressants)
- No controlled trials of ECT in people with ID, but case reports indicate ECT is effective and safe.

PRN Medications

- Pro re nata (Latin for 'in the circumstances')= when needed
- What principles should be used to guide?
- What are the potential problems associated with use of PRN medications?

In conclusion

- Mental disorders are more common in people with ID than the general population
- People with ID experience a number of barriers to timely and effective mental health supports
- People with an ID have the same right to access mental health treatment as anyone else
- The approach to assessment and management required some adaptation
- The same principles apply to treatment for people with and without ID
- But treatment for adults with ID can be more complex
- Optimal treatment
 - Takes into account the particular needs of the individual, including those related to the disability
 - Working with carers
 - Monitoring
 - Multidisciplinary

Free e-learning
intellectual disability mental health



www.idhealtheducation.edu.au



- Introduction to Intellectual Disability
- Living with Intellectual Disability
- Changing Perspectives of Intellectual Disability
- Introduction to Mental Disorders in Intellectual Disability
- Communication: the basics
- Improving your Communication
- Assessment of Mental Disorders in Intellectual Disability
- Management of Mental Disorders in Intellectual Disability
- Coming Soon:
 - interagency work
 - emergency presentations
 - carer intro to mental disorders in people with ID
 - legal and ethical Issues
 - challenging behaviour



The Guide

Accessible Mental
Health Services
for People with an
Intellectual Disability

A Guide for Providers

Available online

3dn.unsw.edu.au

[health.gov.au/internet/
main/publishing.nsf/
Content/mental-pubs](http://health.gov.au/internet/main/publishing.nsf/Content/mental-pubs)

Your Cases

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- National Health and Medical Research Council (NHMRC)
- NSW Institute of Psychiatry
- Autism CRC

