Management of Mental Illness in People with Intellectual Disability: business as usual and COVID-19 considerations

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Funding/disclosures

Core

NSW Ministry of Health

Research and Projects

Family and Community Services NSW

NSW Ministry of Health & Related Organisations

Australian Government Department of Health & Ageing

NDIS Quality and Safeguards Commission

Australian Research Council

National Health and Medical Research Council

Autism CRC

About Us

Introduction

The Department of Developmental Disability Neuropsychiatry (3DN) was established by the Chair of Intellectual Disability Mental Health in 2009. The Chair is funded by **Ageing Disability and Home Care, Family and Community Services NSW** and the **Mental Health Branch, NSW Ministry of Health**.

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3DN Department Head

Professor Julian Trollor
UNSW Chair of Intellectual Disability Mental Health

Learning outcomes

Management of Mental Illness in People with Intellectual Disability: business as usual and COVID-19 considerations

1. Identify risk factors for common mental illnesses in people with intellectual disability
2. Describe core elements of treatment of common mental illnesses in people with intellectual disability, and when/how they should be used
3. Support people with intellectual disability to navigate key aspects of mental health service system
4. Recognise risk and address key element of stress related to CVID-19 in people with intellectual disability

ABOUT INTELLECTUAL DISABILITY

What is intellectual disability?

Below average intelligence

Deficits in adaptive functioning

Onset during developmental period

Intellectual disability terminology

Intellectual disability

Mental retardation

Learning disability

A person with intellectual disability

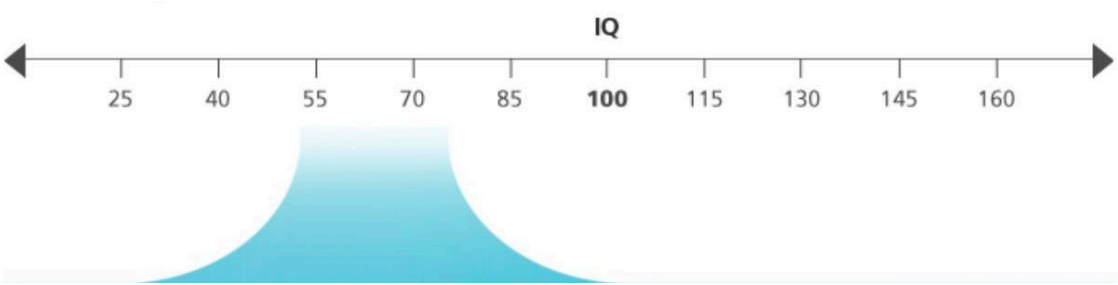
Intellectual disability – Classification

Mild intellectual disability (IQ: 50/55 – 70)

Moderate intellectual disability (IQ 35/40 – 50/55)

Severe intellectual disability (IQ 20/25 – 35/40)

Profound intellectual disability (IQ less than 20/25)



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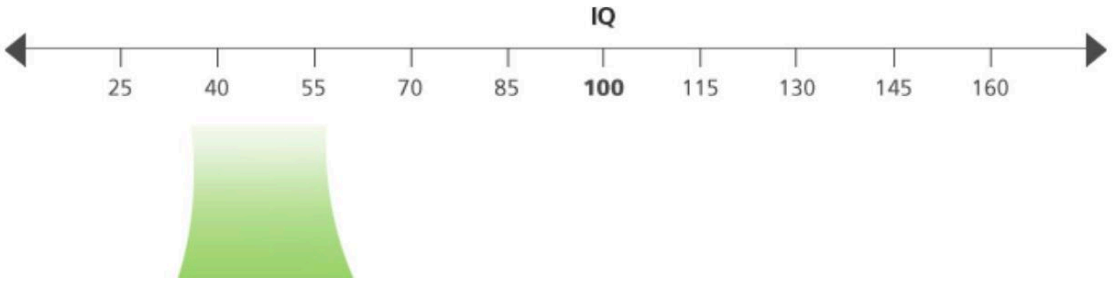

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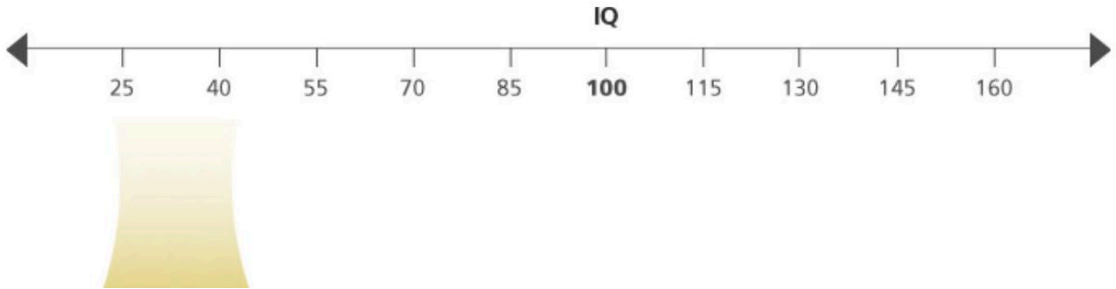

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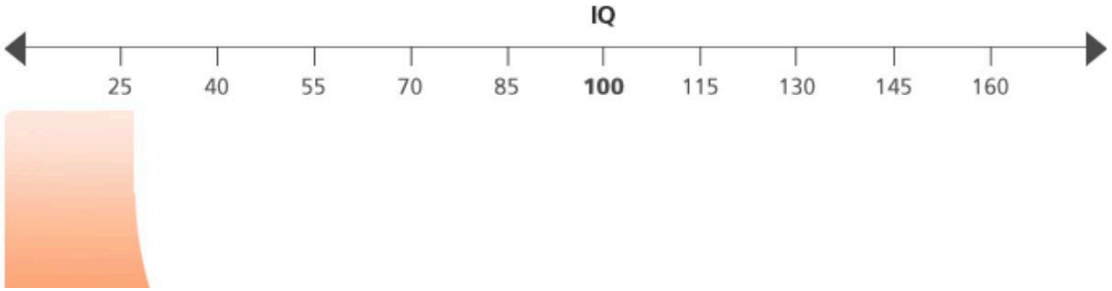
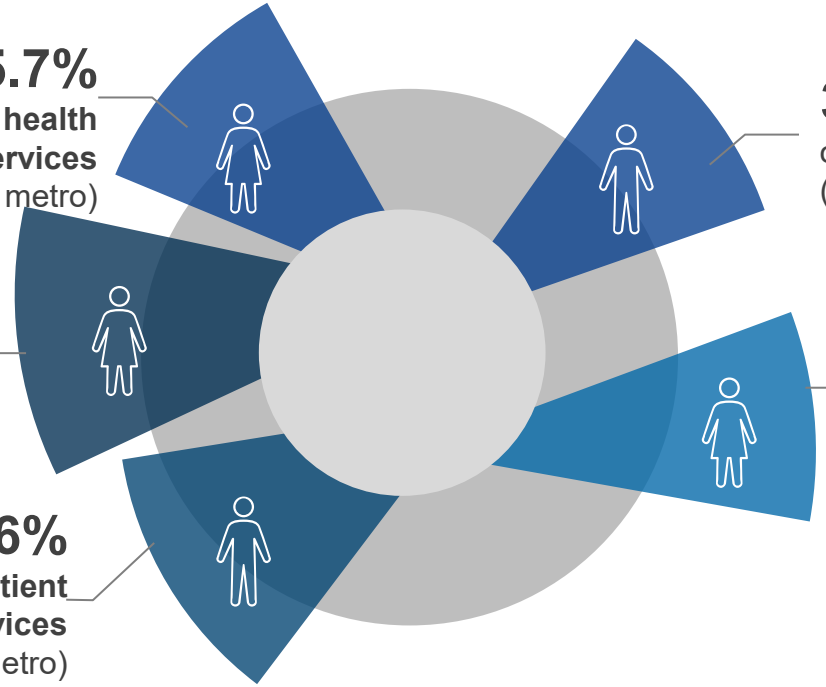


Intellectual disability – Prevalence

Variable across studies

About 1.2%of the population are people with ID who use services

NSW Health service users with ID, FY 14-15



5.7%
of people **using any mental health services**
(6.2% regional, 5.4% metro)

3.8%
of people **using ED services**
(4.3% regional, 3.6% metro)

6.3%
of people **using inpatient mental health services**
(6.8% regional, 6.1% metro)

3.6%
of people **using inpatient non-mental health services** (3.8% regional, 3.6% metro)

5.6%
of people **using non-inpatient mental health services**
(6.2% regional, 5.5% metro)

MENTAL HEALTH: CONTEXT

Oral health

Higher prevalence of poor oral health

Less *access to dental services*, including preventative services.

Wilson, N. J., Lin, Z., Villarosa, A., & George, A. (2018). Oral health status and reported oral health problems in people with intellectual disability: A literature review. *Journal of Intellectual & Developmental Disability* (1-13).
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Primary health care needs

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- half previously undetected
- increased cardiovascular risks, medical consultation rates, hospitalisation and mo

International research in general practice:

- people with intellectual disability have 2.5 times the number of health problems

More recent population-based cohort study of people with intellectual disability reported average of 11.04 co-morbidities per person

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Very high mental health needs

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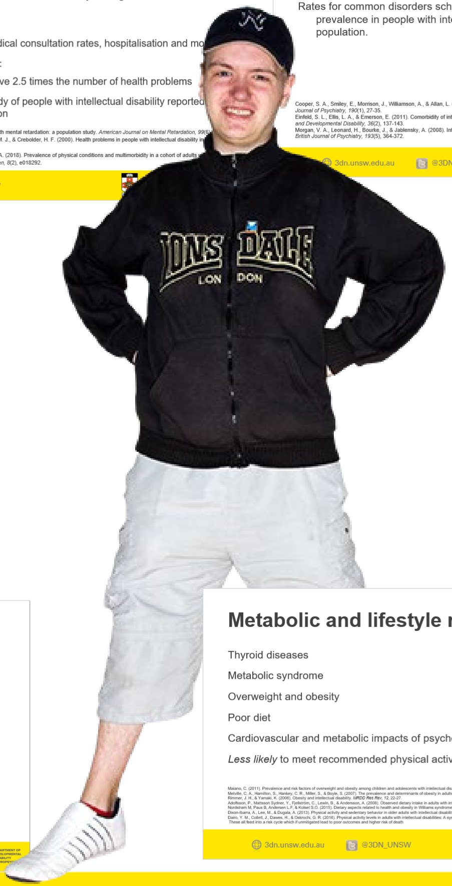

Gastrointestinal system

Dysphagia (difficulty swallowing) rates between 8.1% and 14.4%.

Reflux: GORD in 14.5%- 50%.

Chronic constipation.

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Neuropsychiatric disorders

Epilepsy: meta-analysis of 38 studies in general populations with intellectual disability reported a pooled epilepsy prevalence of 22.2% (95% CI 19.6–25.1).

Dementia

Autism

Tic disorders

Drug induced movement disorders

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Respiratory system

Aspiration

Pneumonia, pneumonitis and lung infections

Metabolic and lifestyle related diseases

Thyroid diseases

Metabolic syndrome

Overweight and obesity

Poor diet

Cardiovascular and metabolic impacts of psychotropic medications

Less likely to meet recommended physical activity guidelines

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These all feed into a risk cycle which if unmitigated lead to poor outcomes and higher risk of death

Markers for Premature ageing elevated

Osteoporosis

Frailty & multimorbidity: younger onset of frailty; similar rates of frailty at age 50 as the general population at age 75

Up to 4-5 X relative risk of dementia in DS; 2-3 times in people with non DS ID

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VULNERABILITY TO MENTAL ILLNESS

Intellectual Disability Mental Health Prevalence

General population

People with

Environmental risk factors

- Living conditions
- Financial difficulties
- Support staff and organisational policies may not support mental health
- Socioeconomic status

Social risk factors

- Social isolation
- Communication difficulties
- Fewer opportunities for meaningful activity
- May have fewer family and friends
- Stigma
- Reduced social and interpersonal skills

Lifestyle risk factors

- More likely to be underweight or obese
- Less likely to exercise
- Difficulties sleeping
- More likely to have contact with the criminal justice system
- Greater effects from drugs or alcohol

Psychological risk factors

- Poor coping strategies
- Negative life events
- Stress and worry
- Low self-esteem or lack of confidence
- Difficulty understanding and labelling emotions
- Lower capacity to process multiple sensory and mental stimuli

Past experiences

- More at risk of, and vulnerable to the effects of bullying, neglect and abuse
- May not be able to express and manage feelings of grief due to reduced cognitive abilities
- Greater likelihood of experiencing unwanted life changes

Biological / physical risk factors

- Genetic risk
- Changes in brain development or functioning
- Physical disability
- Pain and illness
- Multiple medications and side effects
- Sensory impairment

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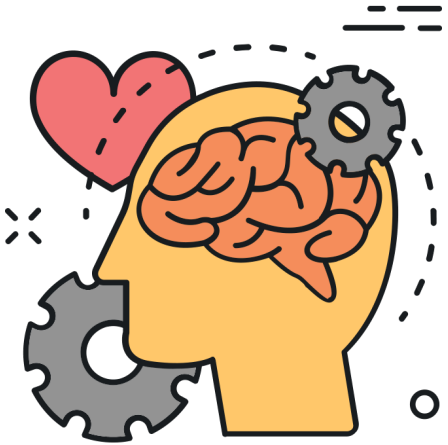

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Socioeconomic status

Importance of baseline and changes from baseline

Basics of assessment

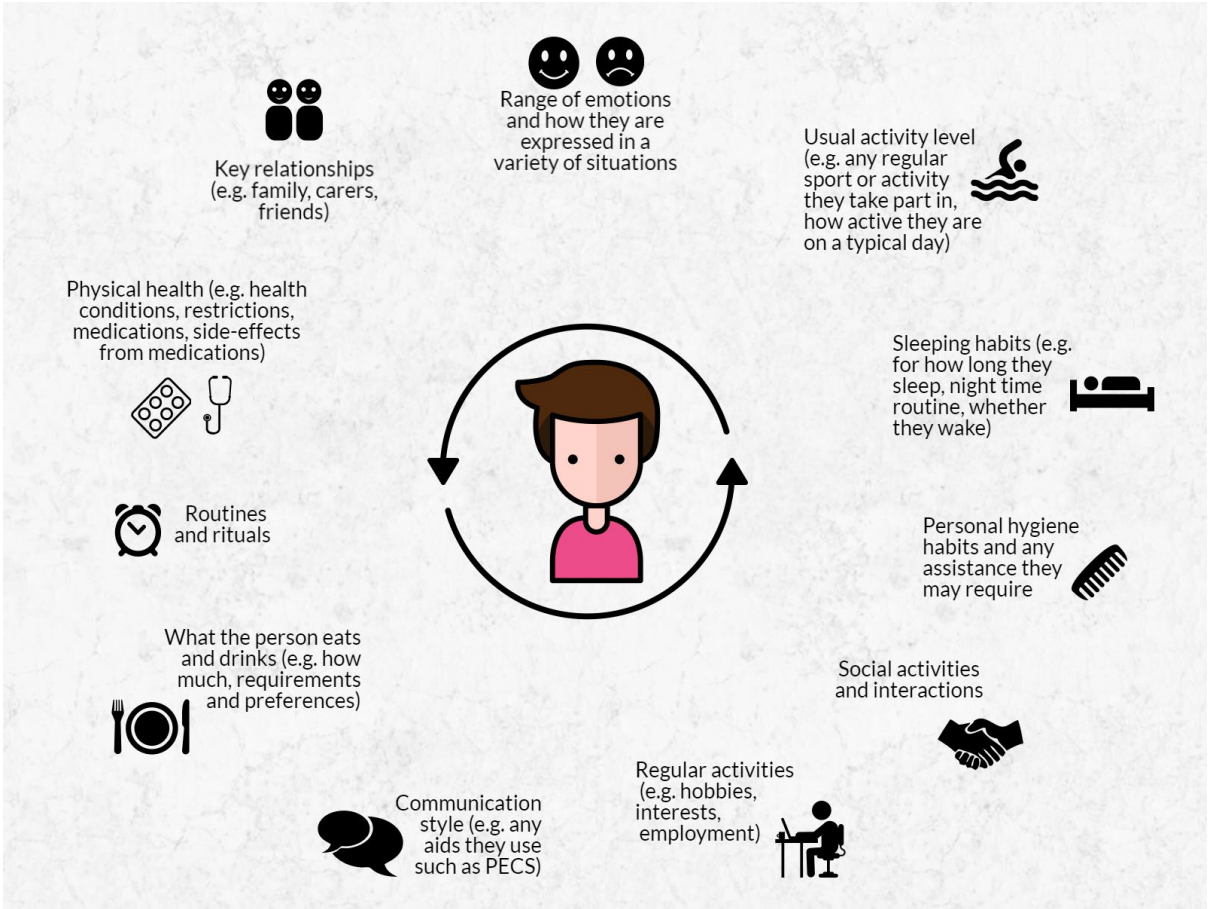
Assessing changes in behaviour

ASSESSMENT

What is “Baseline”

Baseline

- Well being and how this is expressed
- Physical health
- Cognitive abilities and how these are exercised
- Behavioural profile and responses
- Functional abilities

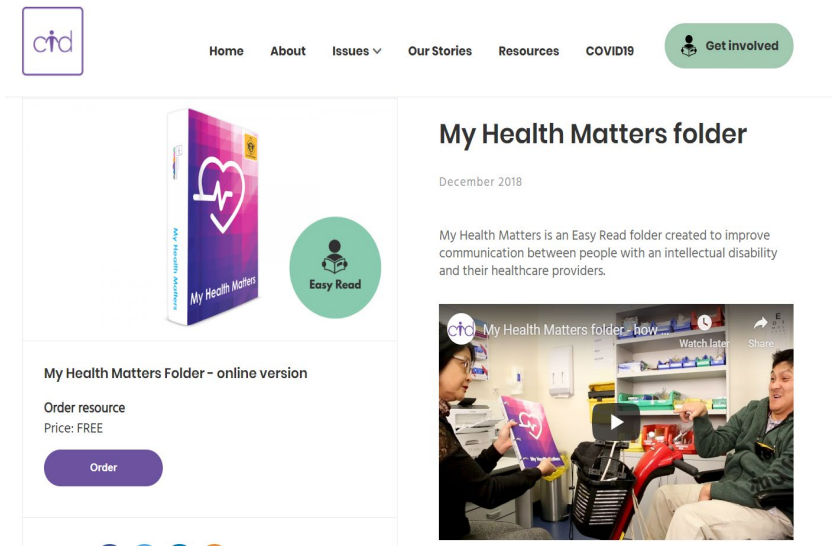

Key relationships (e.g. family, carers, friends)
Range of emotions and how they are expressed in a variety of situations
Usual activity level (e.g. any regular sport or activity they take part in, how active they are on a typical day)
Physical health (e.g. health conditions, restrictions, medications, side-effects from medications)
Sleeping habits (e.g. for how long they sleep, night time routine, whether they wake)
Routines and rituals
Personal hygiene habits and any assistance they may require
What the person eats and drinks (e.g. how much, requirements and preferences)
Social activities and interactions
Regular activities (e.g. hobbies, interests, employment)
Communication style (e.g. any aids they use such as PECS)

What are some of the key sources of information about baseline?

My Health Matters

https://cid.org.au/resource/my-health-matters-folder/

https://www.youtube.com/watch?time_continue=1&v=hV1uezdZj7c&feature=emb_logo

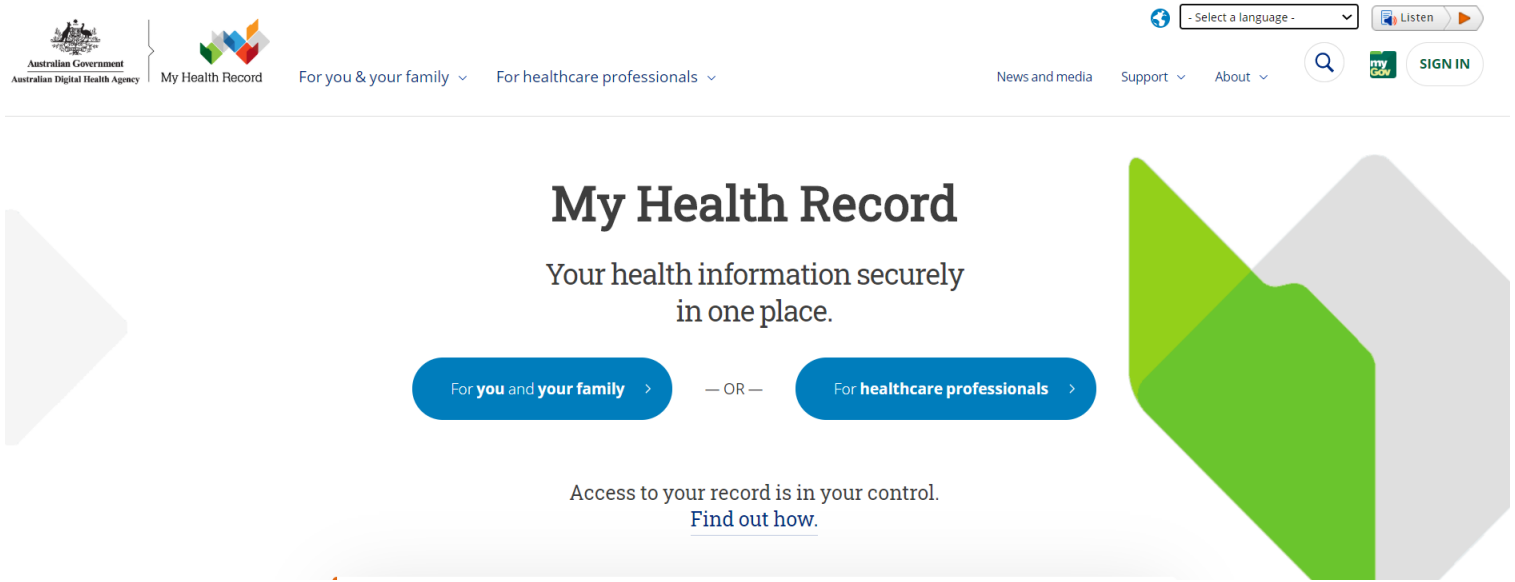


A2D

http://a2d.healthcare/

My Health Record

https://www.myhealthrecord.gov.au/



Comprehensive Heath Assessment Program

https://qcidd.centre.uq.edu.au/resources/chap

The Wellbeing Record

A resource about the person with intellectual disability

- can be used to record their wellbeing and any changes
- helps health professionals understand what wellbeing looks like for the person, and understand any changes

Who is the Wellbeing record for?

- Carers can write in the resource or help the person with ID fill it out
- Health professionals are the main ones who read the resource

How should the Wellbeing record be used?

- Normal Wellbeing section completed for everyone – to create a baseline
- "Changes" section is filled out any time the person or carer notices a change in wellbeing, include when it started, triggers, how long change lasted, etc

How is it used?

- Taken to all appointments with a health or mental health professional to aid discussion about the changes

https://www.3dn.unsw.edu.au/wellbeing-record

Wellbeing record for

Take this booklet to appointments with a health professional together with all other health records, documentation and care plans

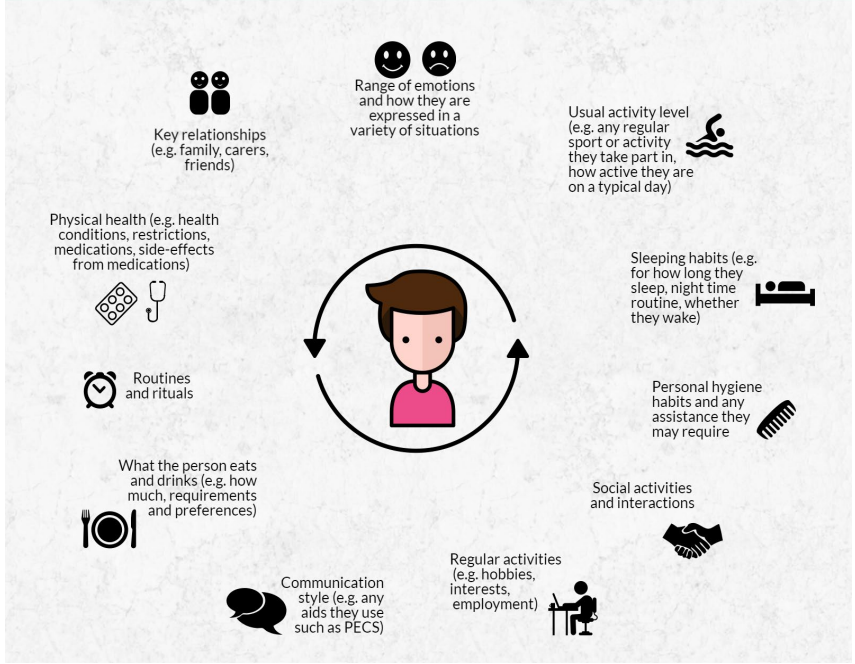
This booklet is for carers to make a written record of wellbeing for a person with an intellectual disability.

This booklet helps carers and health professionals to

- understand what is normal for the person
- recognise and investigate changes.

UNSW AUSTRALIA | 3DN DEPARTMENT OF DEVELOPMENTAL DISABILITY NEUROPSYCHIATRY

What information to record about a person's wellbeing



1. Normal wellbeing

	Describe their normal state of wellbeing. *Date and initial each entry.*
Sleeping habits *Please comment on* - Normal bedtime routine - What they do unassisted - Assistance required - Normal sleep time - Normal wake time - How often they wake in the night - Unusual behaviours eg sleepwalking/talking, nightmares, bedwetting - Any sleep medication (dosage and dates)	
Routines, rituals and behaviours *Includes unique behaviour you have come to know as normal for the person, and behaviours of concern* - When did they begin displaying it? - How often does it happen? - How do you soothe the person? - How do you manage the behaviour?	

How does knowing about baseline assist your assessment?

	People with intellectual disability	People with mild-moderate intellectual disability	People with more severe intellectual disability, or with limited communication skills, or comorbid autism
What is normal and healthy for the individual	A basic normal functional baseline is assumed, and aspects unique to the person are gathered incidentally (e.g. someone's preferences about social contact).	Baseline functioning has some similarities to someone without intellectual disability, but varies and is unique to the individual. Detailed knowledge of the individual's unique baseline will greatly assist in identifying mental disorder.	Baseline functioning and behaviour are unique to each individual. Knowledge of the individual's unique baseline is critical to recognising presentation of mental disorder.
Presentation of mental disorder	• Changes in thought content • Changes in thought form • Emotional changes • Changes in behaviour and functioning	• Changes in thought content (depending on level of communication) • Changes in thought form • Emotional changes apparent in the person's expression, behaviour and functioning • **Greater emphasis** on changes in behaviour and functioning	• Discrete symptoms can be difficult to identify • Behavioural analysis and third party reports rather than self-reported symptoms • Emotional changes apparent in the person's expression, behaviour and functioning • **Greater emphasis** on changes in behaviour and functioning

“Changes caused by a mental illness are often overlooked and perceived as normal in the context of the intellectual disability”

Examples

- the expression of grandiosity in bipolar disorder may appear relatively mundane. eg imitating a staff member, or talking about driving (when the person doesn’t actually drive)
- pacing or throwing furniture might be interpreted as an expression of anger or anxiety, when in reality the person is experiencing mania
- sleeping more and being less interested in normal activities may be interpreted as related to lower level of cognitive capacity instead of depression.

Behaviours that seem to indicate a mental illness may have other causes

- An idiosyncratic response to a stressor that reflects a unique coping strategy may be incorrectly interpreted as bizarre or psychotic. For example, if the person is responding to stressful events with increasing agitation and giggling.
- Sleep disruption, reduced activity and increase in agitation may in fact be due to pain or discomfort from a medical condition such as arthritis, rather than depression or anxiety disorder.
- In a person with limited communication skills, no longer wishing to engage in an activity may appear to be a symptom of depression, but they may also have simply outgrown the activity or no longer find it rewarding.
- A person may appear to have depression or even dementia symptoms as a result of a medical condition which causes underactivity of the thyroid gland.
- Just as for the general population, increased crying and sleep problems may relate to grief/bereavement. This may include the loss of a close friend through means other than death, for example, a group home member who has moved out, or a co-worker who has left their job.

PRACTICAL CONSIDERATIONS FOR CONSULTATIONS

Before the Consultation

- Find out about the person's:
  - needs before the consultation from e.g. mobility or sensory needs
  - preferred communication methods and any aids to communication that are required (from individual, referrer or support person)
  - level of independence, and whether any support persons will need to be involved at the assessment
- Book extra time for the assessment:
  - to build rapport
  - consider longer appointment or 2 appointments
- Simplify appointment and referral letters; use easy read, make reminder phone calls
- Consider home visit, or if not possible consider suitability of the environment, pre-visit to the clinic for familiarisation
- Ask for consent to access other relevant health records
- Avoid cancelling at short notice; prepare the person for and changes to arrangements

During the Consultation

- avoid long waiting times
- review in setting that is familiar to them e.g. their home, school or day centre;
- consider the need to reduce stimulation:
  - waiting in quiet area
  - see the person in a suitable space to reduce stress
- greet the person with an intellectual disability first, speaking to them directly
- if a family member or support person is present, check if the person with ID consents for them to be involved in the consultation
- check whether the individual would like to speak with you alone.

IMPORTANT CONCEPTS TO REMEMBER DURING FOR CONSULTATIONS

Diagnostic overshadowing

- Behavioural change is a common reason for presentation to GPs, EDs and mental health services in people with an intellectual disability.
- Diagnosis of a serious mental health issue can be missed if the behaviour is automatically attributed to the person's intellectual disability.
- This is termed 'diagnostic overshadowing'
- Can result in under-diagnosis and under-treatment
- Always conduct an assessment, even if unsure whether the presentation indicates a mental disorder

Complexity

- Assessment and diagnosis can be complex because of level of ID, complexity such as higher rates of comorbid medical/physical/sensory conditions, other disabilities, and polypharmacy.
- Medical conditions and medications can have a significant impact on a person's psychological functioning
  - May induce psychiatric disorder (e.g. depression)
  - May mimic psychiatric disorder (e.g. sedation/amotivation side effects of medication may be mistaken for apathy/withdrawal of depression).
- Particular syndromes are associated with psychiatric and medical conditions, (e.g. Fragile-X syndrome is associated with anxiety, hyperactivity, hyper-arousal and autism spectrum disorders).
- Remember: importance of detailed history and examination; knowledge about baseline

Complexity

- Presentation may vary greatly in different contexts
  - is it worse in some contexts? (home, day programs, time spent with specific people or places)
- Identifying the causes of changes in behaviour and functioning is more complex because of challenges in multiple areas (e.g. physical health, social situations and housing)
- Collect assessment information on all relevant dimensions:
  - developmental, biomedical, psychiatric, psychological/cognitive/social, adaptive behaviour, functional abilities, environmental, cultural, and educational history.

Behavioural Phenotypes

- Certain genetic disorders that cause intellectual disability are associated with particular patterns of behaviour called behavioural phenotypes
  - e.g. Prader-Willi syndrome: poor impulse control, disturbance of satiety, obsessions, compulsions, and poor control over emotions such as anger.
- Becoming familiar with behavioural phenotypes can help clinicians interpret symptoms and formulate management plans.
- Information from medical records, research, and specialists. Also see the Society for the Study of Behavioural Phenotypes website for more information http://www.ssbp.org.uk/syndromes.html.

Atypical symptoms

Symptoms of mental ill health are more likely to be atypical or behavioural in nature for people with an intellectual disability. Therefore, changes in behaviours should be investigated, rather than dismissed as 'disruptive' or a 'learned' behaviour.

- *Observation*
  - Observation can be an important tool when assessing an individual with an intellectual disability, especially someone with communication difficulties. Behaviour to observe includes how the individual interacts with you and others.
  - Using observational records such as sleep, weight and ABC charts are also valuable tools for others to observe behaviour when the mental health professional cannot.

Assessment tools

- Assessment tools to aid understanding of the person's presentation
- Some assessment tools developed or adapted for people with an intellectual disability
- Self or informant reports
- **See *Intellectual Disability Mental Health Core Competency Framework: A Practical Toolkit for Mental Health Professionals***

Diagnostic manuals

Diagnostic Manual – Intellectual Disability (DM-ID-2): A Textbook of Diagnosis of Mental Disorders in Persons with Intellectual Disability; Eds Fletcher, Barnhill, Cooper, ISBN# 1-57256-134-3

DC-LD (Diagnostic criteria for psychiatric disorders for use with adults with learning disabilities); Royal College of Psychiatrists 2001; ISBN 1-901242-61-7

After the assessment

- Consider repeating if appropriate (e.g. if the individual was tired, unwell, or presentation was ambiguous).
- With consent, chase missing information
  - From family, support persons and services, other health/allied health professionals and services, schools and educational settings
- Communicate with the person with an intellectual disability and family and support networks about the preliminary outcome
- Prepare all involved for what the treatment process will involve, and tell them about informed consent and the right to participate.

The basics

TREATMENT


LON DON

Recovery oriented practice

- View the individual with an intellectual disability as an expert in their own life
- Identify recovery outcomes
- Help people to take as much responsibility for their lives as possible
- Focus on holistic care
- Plan for long-term support and ongoing wellbeing
- Involve, as appropriate, the individual, mental health professionals, disability and health services, and support networks
- Devise a comprehensive mental health care plan including strategies for crisis prevention, early intervention, ongoing management strategies and, follow-up
- Regular monitoring and review which includes support networks

Psychological interventions

First-line eg mild depression and mild anxiety

Adjunctive in more severe disorders

Use regular therapy techniques with some modifications

- *Behavioural therapies*- for irritability or aggression, and to help manage activity scheduling
- *Cognitive behaviour therapy*- for example depression, anxiety, eating disorders, substance use, personality disorders, trauma, anger and aggression. Adaptations: longer periods to build rapport, simplified explanations of models and concepts, less complex homework tasks and engaging a support person as a co-therapist.
- *Dialectical behaviour therapy*- esp for those who have a personality disorder
- Other therapies: supportive therapy, family systems therapy (for both individuals living with their family and in group homes) and psychodynamic therapy

How to modify psychological treatments

Figure 4. Modifications to psychological therapy for people with an intellectual disability

Practical adjustments		• Flexible timing, e.g. spending more time building rapport, repeating concepts and material, moving through each step more slowly, having breaks or shorter sessions, and more sessions if required. • Flexible location, e.g. visits to the individual's home may assist engagement.
Involving others		• Family and support people can assist your communication with the individual regarding explaining and implementing psychological interventions. • Psychoeducation can also be provided to the support person regarding the individual's treatment, how they can support therapy strategies (e.g. encouraging self-soothing), and how they can assist with homework tasks. • Support persons can help the individual implement recommended lifestyle changes, and assist with monitoring and seeking follow-up.
Focusing on practical and concrete elements of therapy		• Abstract concepts, which are often discussed in therapy (such as assumptions, empathy and relationships between ideas), can be difficult to grasp for people with an intellectual disability. Reducing the focus on cognitive components, and increasing the focus on behavioural components, is often required. • While working with core thoughts and schemas can be effective for people with borderline/mild intellectual disability (with simplified concepts), for people with moderate to severe intellectual disability, focusing on strategies to manage behaviour and emotions can be more effective. • Simplify psychoeducation provided. • Rather than written notes, clinicians can go through handouts (e.g simplified visual guides) with the individual to ensure they understand all points or steps. • Interventions should be customised to suit the individual's cognitive and language skills e.g. by using diagrams (such as a thermometer to monitor mood), visual cues, pictures, stories and role plays to convey concepts. • Try using homework tasks that are activity based, for example role plays with friends or family. • Applied behavioural analysis can be used before implementing environmental changes that may be maintaining, for example, anxiety or depressed mood.
Handling stigma and discrimination		• People with an intellectual disability often face issues in life that most do not, such as real stigma, discrimination and social exclusion. It is important not to dismiss thoughts regarding issues such as social exclusion as merely a result of low self-esteem or paranoia. Therapy may include helping the individual to live with such situations and to respond appropriately.

See more information in our IDMH e-learning, competency framework and competency toolkit

Pharmacotherapy

- Common for psychotropic medications to be inappropriately prescribed for people with an intellectual disability
  - Excess use, dose and poorly targeted in challenging behaviour
  - Prolonged treatment
  - Polypharmacy common
  - Poor monitoring for side effects
- Pharmacological interventions:
  - are indicated as primary treatment in many mental disorder as with the general population
  - principles of prescribing are the same as for the general population

General guidelines for prescibing

Table 6. General guidelines when prescribing psychotropic medications to people with an intellectual disability

Before Prescribing	When Choosing Psychotropic	During Treatment
Determine if prescription is warranted. Is there: • A confirmed diagnosis of mental illness for which psychotropics are indicated AND/OR • Challenging behaviour that is severe and non-responsive to maximal cognitive or behavioural therapy, and is significantly affecting the person's or family/ support persons' life. • Evidence that potential benefits outweigh the risks. Develop a treatment plan detailing: • The person's communication needs. • Targeted behaviour/symptom, frequency and intensity. • How you and others will measure impact of medication on behaviours/symptoms including how effects and side effects will be assessed. • All prior assessments of medical, psychiatric and functional causes of the behaviour/symptom. • Past response to treatment including side effects. • A treatment timeline and plan following the trial. Obtain consent from the individual and/or appointed decision maker.	Consider medical comorbidities and potential medication interactions: • Some syndromes have an increased frequency of cardiometabolic, respiratory disorders or dementia. Avoid medications that will worsen these. • Epilepsy: additional monitoring may be required when prescribing psychotropics that lower the seizure threshold. Consider: • Expressed wishes of the person and primary support persons. • Monitoring requirements of the psychotropic (e.g. blood tests) and whether the person will realistically be able to meet them. • Swallowing or absorption impairments. • Past response to treatment including side effects. • Reviewing co-prescribed psychotropics and taking steps to reduce polypharmacy. • The cardiometabolic liability of the psychotropic.	Commencing Treatment: • Educate the person and their support persons about the psychotropic, indications for treatment and side effects. • Obtain baseline cardiometabolic data. • Commence on a low dose and increase gradually if required. Monitoring Treatment: • Engage the person and their support persons in the monitoring process. • Set regular review times and a timeframe for treatment. • Remember that side effects may be difficult to recognise and report. • Watch for sudden behavioural changes after initiating treatment or increasing dose as this may indicate adverse effects. • Monitor adverse effects on medical comorbidities. Discontinuing Treatment: • Consider discontinuation if ineffective; unacceptable side effects; discontinuation is requested; symptoms have resolved and/or medication is no longer required. • Taper slowly. Avoid simultaneous withdrawal of anticholinergic agents or multiple psychotropics.

See our article
https://www.nps.org.au/australian-prescriber/articles/prescribing-psychotropic-drugs-to-adults-with-an-intellectual-disability

See our 8 detailed podcasts
https://www.3dn.unsw.edu.au/education-resources/health-mental-health-professionals/positive-cardiometabolic-health-people-id/responsible-psychotropic-prescribing-people-intellectual-disability-podcasts

To manage cardiometabolic risk see our resources positive cardiometabolic health for people with intellectual disability

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When should I seek specialised review?

- Symptoms do not get better
- Symptoms worsen despite treatment (e.g. depression symptoms do not get better with the standard age-appropriate intervention)
- Complex presentations (e.g. severe intellectual disability, the presence of a complex genetic disorder with medical comorbidity, and psychotic symptoms)
- Nature of the problem is uncertain despite thorough initial assessments
- Condition or treatment requires specialised psychotherapeutic or pharmacological skills
- Deteriorating or unexpected course
- Continuing high risk to the individual despite treatment (self-harming behaviour or expressed suicidal ideation).

COVID-19 CONSIDERATIONS

COVID-19 and Intellectual Disability

People with intellectual disability:

- Slow to be recognized as vulnerable group
- Often not included in initiatives to reduce risk and spread
- Specific vulnerabilities related to health, frailty, care context and proximity/mobility of care staff

COVID-19 and Intellectual Disability

At risk population: NY example

Case rate 4 x

Mortality 2 x

Contents lists available at ScienceDirect

Disability and Health Journal

journal homepage: www.disabilityandhealthjnl.com

ELSEVIER

Brief Report

COVID-19 outcomes among people with intellectual and developmental disability living in residential group homes in New York State

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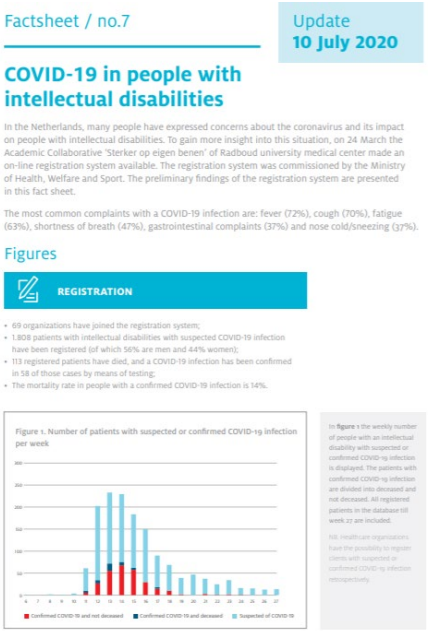
ABSTRACT

Background: People with intellectual and developmental disabilities (IDD) may be at higher risk of severe outcomes from COVID-19.
Objective: To describe COVID-19 outcomes among people with IDD living in residential groups homes in the state of New York and the general population of New York State.
Methods: Data for people with IDD are from a coalition of organizations providing over half of the residential services for the state of New York, and from the New York State Department of Health. Analysis describes COVID-19 case rates, case-fatality, and mortality among people with IDD living in residential group homes and New York State through May 28, 2020.
Results: People with IDD living in residential group homes were at greater risk of severe COVID-19 outcomes: case rates – 7,841 per 100,000 for people with IDD compared to 1,910 for New York State; case-fatality – 15.0% for people with IDD compared to 7.9% for New York State; and mortality rate – 1,175 per 100,000 for people with IDD compared to 151 per 100,000 for New York State. Differences in cases and mortality rate were confirmed across regions of the state, but case-fatality rate was only higher for people with IDD in and around the New York City region.
Conclusions: COVID-19 appears to present a greater risk to people with IDD, especially those living in congregate settings. A full understanding of the severity of this risk will not be possible until US states begin publicly sharing all relevant data they have on COVID-19 outcomes among this population.

COVID-19 and Intellectual Disability

At risk population: Netherlands example

Mortality 14% (gen. population case fatality rate 11.8%)



Factsheet / no.7

Update
10 July 2020

COVID-19 in people with intellectual disabilities

In the Netherlands, many people have expressed concerns about the coronavirus and its impact on people with intellectual disabilities. To gain more insight into this situation, on 24 March the Academic Collaborative 'Sterker op eigen benen' of Radboud university medical center made an on-line registration system available. The registration system was commissioned by the Ministry of Health, Welfare and Sport. The preliminary findings of the registration system are presented in this fact sheet.

The most common complaints with a COVID-19 infection are: fever (72%), cough (70%), fatigue (63%), shortness of breath (47%), gastrointestinal complaints (37%) and nose cold/sneezing (37%).

Figures

REGISTRATION

- 69 organizations have joined the registration system;
- 1.808 patients with intellectual disabilities with suspected COVID-19 infection have been registered (of which 56% are men and 44% women);
- 113 registered patients have died, and a COVID-19 infection has been confirmed in 58 of those cases by means of testing;
- The mortality rate in people with a confirmed COVID-19 infection is 14%.

Figure 1. Number of patients with suspected or confirmed COVID-19 infection per week

Why are people with ID vulnerable during the COVID-19 pandemic?

People with intellectual and developmental disability are:

- highly vulnerable groups and often have complex comorbidities and pre-existing health conditions
- likely to be at higher risk of acquiring COVID-19 and of poor health outcomes associated with COVID-19
- potentially more vulnerable to effects on mental wellbeing from the COVID-19 pandemic
- need reasonable adjustments to be made to ensure their access to healthcare.

Why are people with ID more likely to experience mental ill health during the COVID-19 pandemic?

Mental illness and behaviours of concern may rise due to:

- individual risk factors such as severity of disability, presence of autism spectrum disorder, age, experience of abuse, and pre-existing mental health issues and behaviours of concern
- difficulty adjusting to disruption of routine and to risk reduction strategies including social distancing, isolation or quarantine
- higher reliance on families, disability support workers and other service providers
- heightened concern and risk of poor health outcomes from COVID-19
- difficulty understanding COVID-19 information and necessary changes, expressing concerns, and accessing appropriate supports at this stressful time.

What is the role of health and mental health professionals?

When providing support to a person with ID, health and mental health professionals should consider:

- proactively providing mental health check-ins with the person and their supporters
- ensuring people know when and how to access mental health and behavioural supports during the COVID-19 pandemic, and specifically discuss how consultations can be accessed (e.g. telehealth)
- update the persons mental health care plan and provide a copy for the patient, family and/or their disability support workers where appropriate.

How can you help reduce anxiety and stress?

- encourage people with disability and those who support them to seek information from trusted sources at regular intervals.
- avoid focus on negative news items for both the person and their supporters.
- encourage the person and their supporters to proactively seek positive stories about coping during the pandemic and recovery from the virus.
- encourage regular opportunities for the person to express their feelings and check their understanding and use of social stories or materials that allow them to process the situation at their own pace.

How can you help reduce anxiety and stress?

Disruptions to routines and changes in disability support staff can be difficult for people with intellectual or developmental disability:

- maintain usual routines that are aligned to COVID-19 safety recommendations
- incorporate new activities which reinforce COVID-19 preventive measures
- continue connection with loved ones and friends. If direct contact is not possible, consider using scheduled telephone and/or video conferencing
- ensure daily exercise and healthy eating and sleeping routines.

How should I manage mental health and behavioural concerns?

- All treatment should be in accordance with best practice guidelines
- Medical practitioners should be cautious about diagnosis and treatment of mental health conditions in people with intellectual and developmental disability in the COVID-19 context, and a low threshold for seeking additional specialist mental health review is encouraged
- First line treatment for mild to moderate mental illnesses: psychological treatments and environmental strategies
- More severe mental illness may require psychotropic medication treatment

How should I manage mental health and behavioural concerns?

- For escalations of behaviour:
  - review adherence to the Behaviour Support Plan or advocate for behaviour support if none provided.
  - ensure adequate input from the behaviour support specialist
- Avoid initiation or escalation of psychotropic medication for behaviours in the absence of an underlying mental health cause. This does not represent best practice and can mask the underlying cause of the behavioural escalation
- Minimise disruptions to therapy services and medications (e.g. online or telehealth appointments, scripts)
- Ongoing reviews of mental health by using telehealth appointments and telehealth MBS items, noting the bulk billing incentives currently in place

COVID-19 Advice

https://www.health.gov.au/news/health-alerts/novel-coronavirus-2019-ncov-health-alert/advice-for-people-at-risk-of-coronavirus-covid-19/coronavirus-covid-19-advice-for-people-with-disability

https://www.health.gov.au/news/health-alerts/novel-coronavirus-2019-ncov-health-alert/coronavirus-covid-19-advice-for-the-health-and-aged-care-sector/providing-disability-support-services-during-covid-19

COVID-19 Health Professionals Disability Advisory Service: 1800 131 330

This service provides specialised advice to health professionals responsible for the medical care of people with disability diagnosed with COVID-19 or experiencing symptoms. Health professionals can call from 8am to 9pm (AEST) Monday to Friday. This service is available until 17 November 2020.

RESOURCES

Comprehensive overview of Tools and Resources

https://www.3dn.unsw.edu.au/IDMH-CORE-COMPETENCY-FRAMEWORK

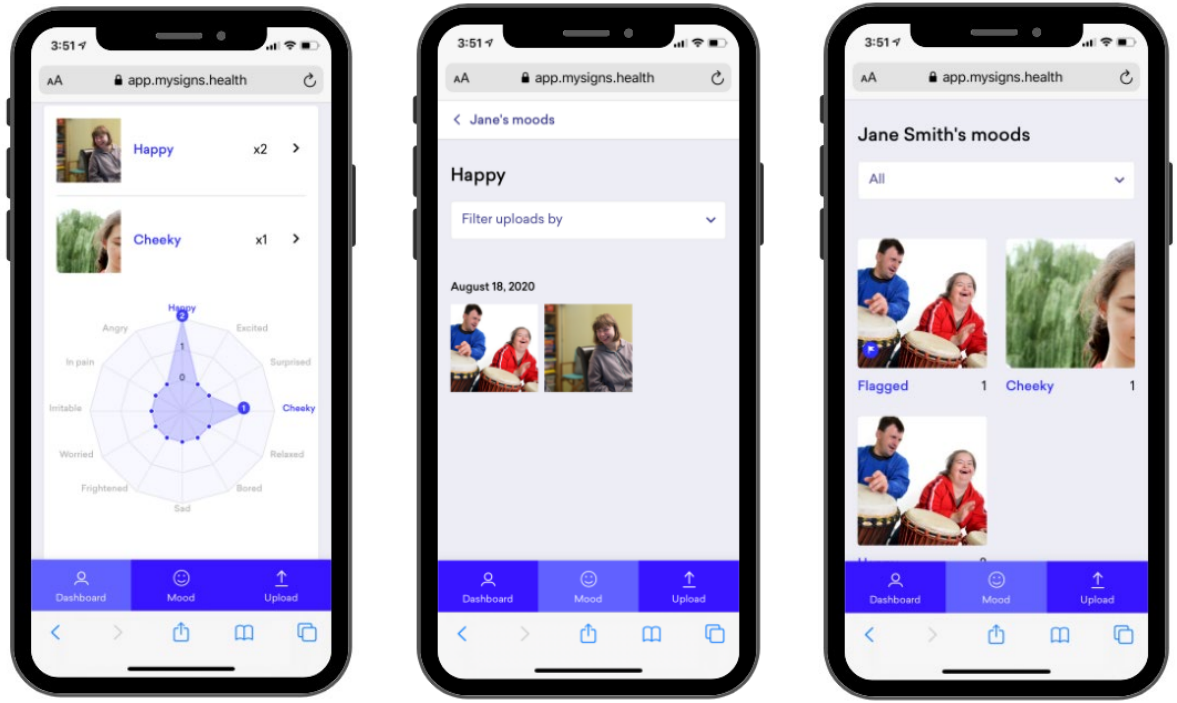
NEW TOOLS AND RESOURCES

MySigns

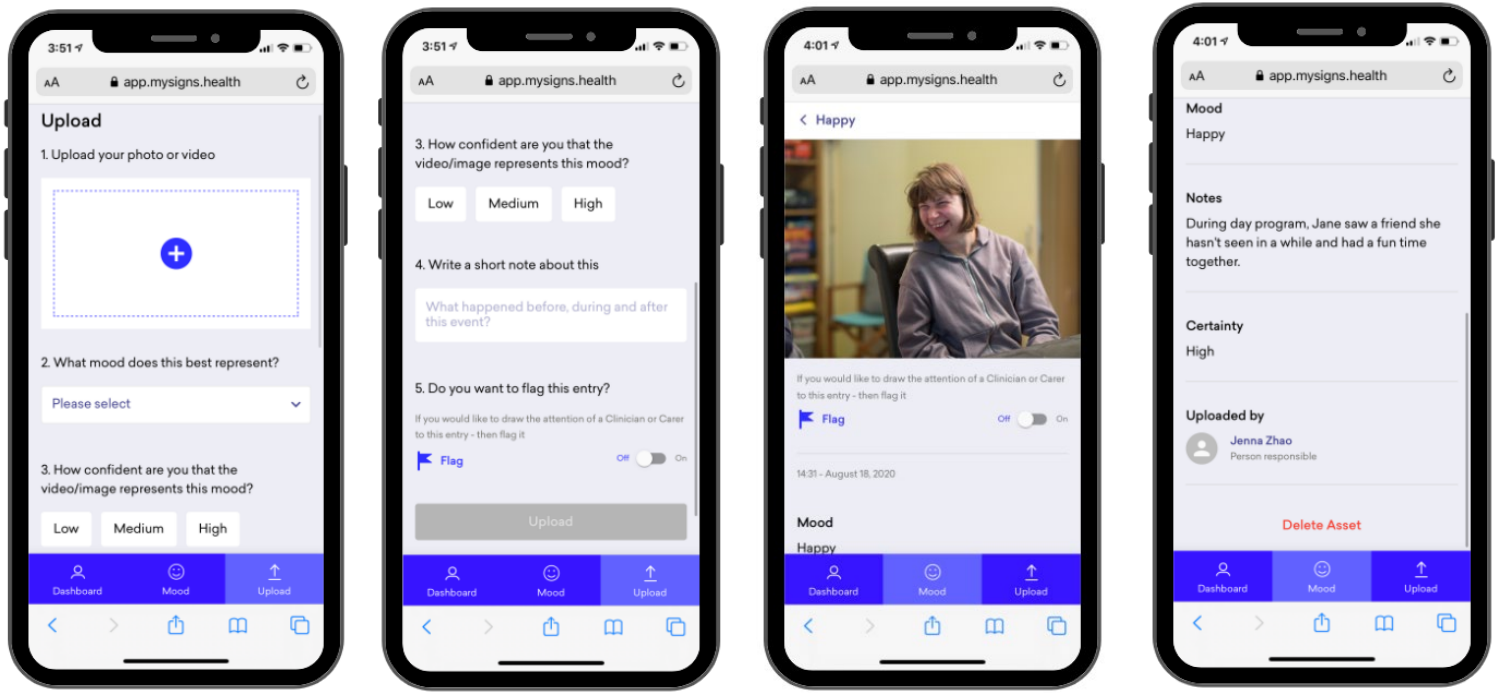
www.mysigns.health

- People with ID and communication impairments often display information about their mental health through unique behaviours, gestures and expressions
- Mental health clinicians may not know the person well enough to interpret these behaviours, gestures and expressions
- MySigns allows carers and other supporters to capture and share information they have observed with clinicians
- MySigns is:
  - Free to use
  - One of very few available digital mental health tools for people with ID
  - Available to anyone with a phone or computer with internet connectivity

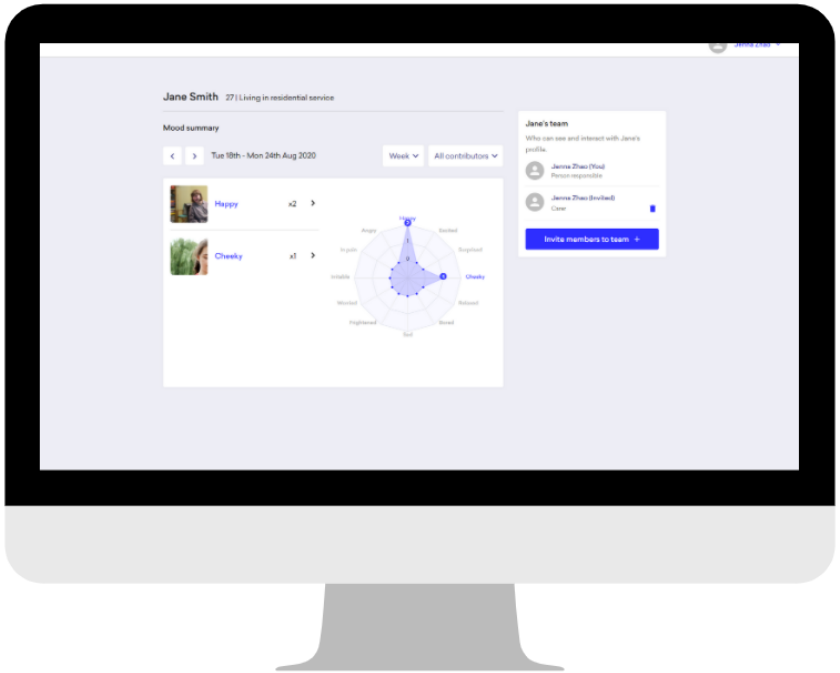
Mobile view – dashboard & mood library

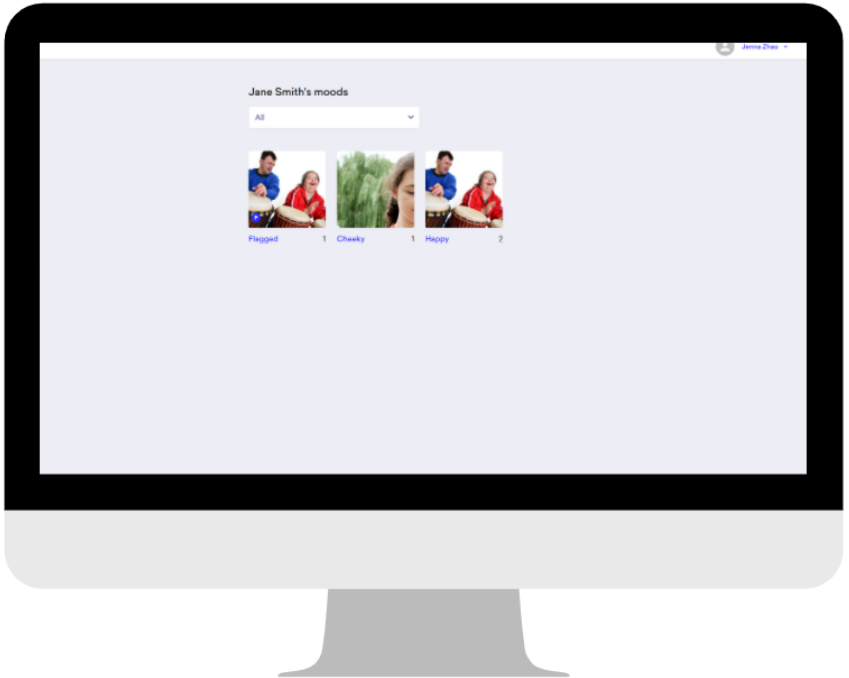


Mobile view – uploading assets



Desktop view – dashboard & mood library





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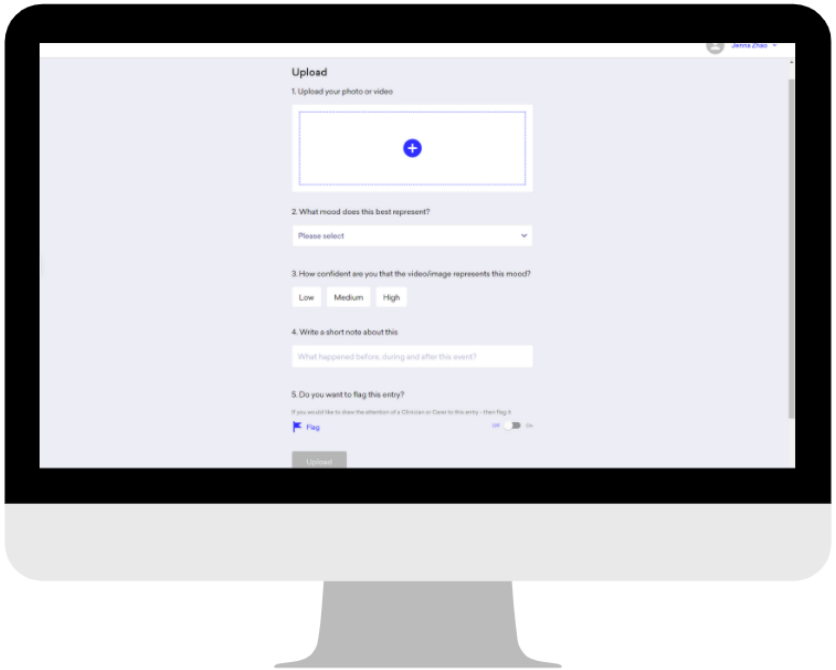
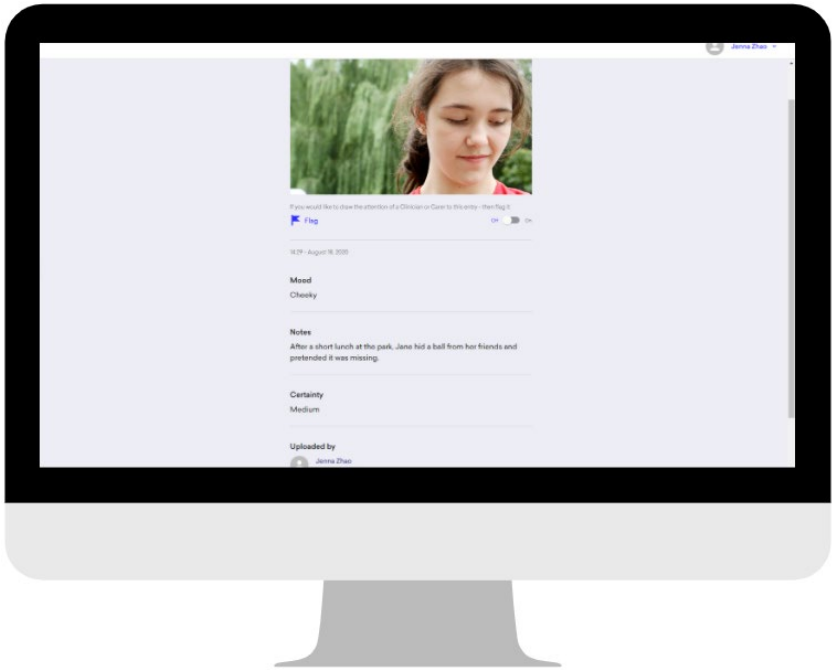




Mental Health Service Easy Read resources

- Coming soon www.3dn.unsw.edu.au/projects/easyread

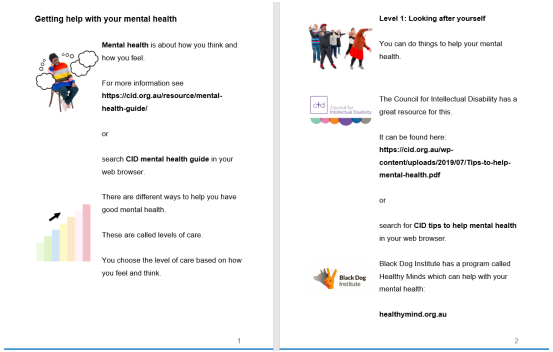
- People with ID and other cognitive disorders can experience communication difficulties that prevent them from accessing and participating in mental health care.
- Accessible information is important to promote the best health outcomes.
- Scoping work identified gaps in the availability of Easy Read versions of key documents within NSW mental health services.
- Easy Read materials adapt standard information into a briefer copy using simple language and pictures.

Mental Health Service Easy Read resources

- 3DN has developed a **series of Easy Read resources** providing information about accessing and navigating public mental health services available within NSW across 4 topic areas.
- Consultation was undertaken with:
  - NSW Health Mental health services
  - People with ID and their support networks
- Development of the resources used a co-design approach.
- A toolkit will also provide information on how to support individuals to use the resources.

Easy Read resource topic areas

1. **Navigating the mental health service sector and questions to ask**
    - Introduction to mental health services and professionals depending on level of need.
2. **Introduction to key sections of the Mental Health Act**
    - Information on types of admission, CTOs, the Mental Health Review Tribunal, and the role of family and friends.



Getting help with your mental health

Mental health is about how you think and how you feel.

For more information see **https://cid.org.au/resource/mental-health-guide/**

or

search **CID mental health guide** in your web browser.

There are different ways to help you have good mental health.

These are called levels of care.

You choose the level of care based on how you feel and think.

1

Level 1: Looking after yourself

You can do things to help your mental health.

The Council for Intellectual Disability has a great resource for this.

It can be found here: **https://cid.org.au/wp-content/uploads/2019/07/Tips-to-help-mental-health.pdf**

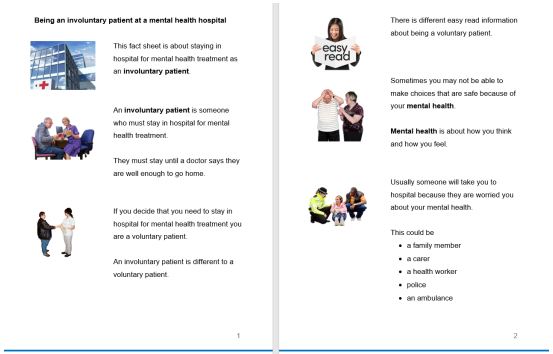
or

search for **CID tips to help mental health** in your web browser.

Black Dog Institute has a program called Healthy Minds which can help with your mental health:

healthymind.org.au

2



Being an involuntary patient at a mental health hospital

This fact sheet is about staying in hospital for mental health treatment as an **involuntary patient**.

An **involuntary patient** is someone who must stay in hospital for mental health treatment.

They must stay until a doctor says they are well enough to go home.

If you decide that you need to stay in hospital for mental health treatment you are a voluntary patient.

An involuntary patient is different to a voluntary patient.

1

There is different easy read information about being a voluntary patient.

Sometimes you may not be able to make choices that are safe because of your **mental health**.

Mental health is about how you think and how you feel.

Usually someone will take you to hospital because they are worried you about your mental health.

This could be

- a family member
- a carer
- a health worker
- police
- an ambulance

2

Easy Read resource topic areas

3. **Easy Read summaries of Statement of Rights documents**
    - To support understanding of official documents provided to involuntary, voluntary, and CTO patients.
4. **Orientation to inpatient mental health services**
    - Series of information sheets for people receiving care in inpatient services.
    - Modifiable template that services can adapt to meet their needs.

Rights for voluntary patients

This information sheet is about your rights when you stay at a mental health hospital as a **voluntary patient**.

A **voluntary patient** is someone who has decided to stay in hospital for mental health **treatment**.

Treatments are things that can help you feel better.

Your rights in hospital

You do not have to stay in hospital if you do not want to.

3

You need to talk to mental health workers before you leave.

Mental health workers might say you need to wait and see a doctor before you leave.

Mental health workers are people who work to help you with your mental health.

A doctor needs to see you less than 2 hours after you arrive at hospital.

The doctor will decide if you can go home.

You only stay in a mental health hospital as long as you need to **recover**.

Recover means getting better so you can do the things you usually do.

4

What happens when I arrive at hospital

This easy read information sheet is about what happens first when you arrive at hospital.

<Modify to reflect order of events and add any additional admission procedures>

What happens when I arrive

When you arrive at the hospital <insert appropriate person> will show you

- your room
- the bathroom
- where you eat meals
- the activities room
- where you see your <health care team>

<Insert other applicable places>

[If available] <Insert appropriate person> will give you a map of the <unit/ward>.

12

You will have a name tag on your wrist.

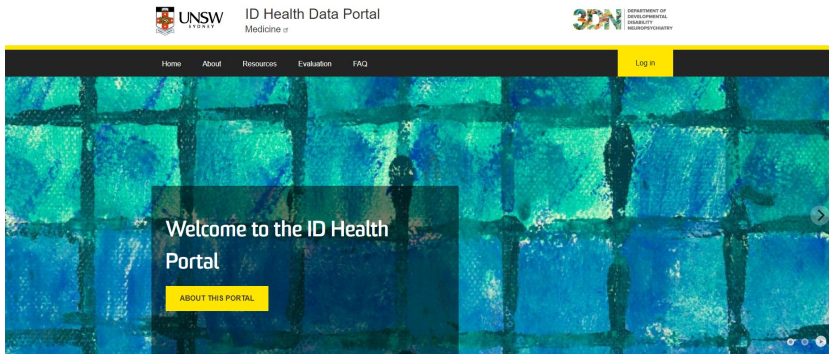
You will talk to a doctor soon after you arrive.

<Insert appropriate person> will introduce you to people who work at the hospital.

You will meet the people who will care for you while you are in hospital.

13

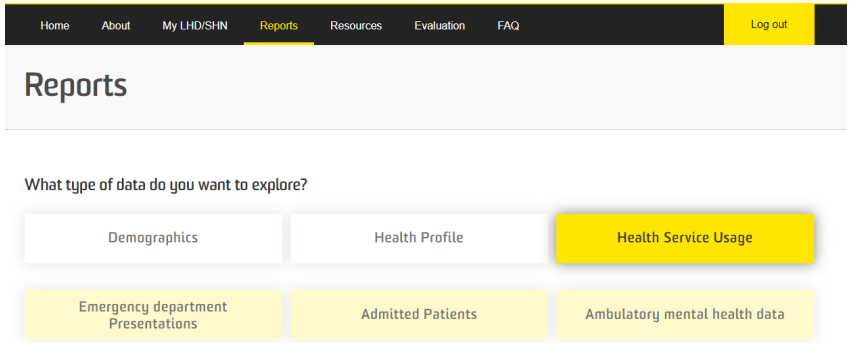
ID Health Data Portal



https://idhealthdataportal.unsw.edu.au/

The Portal is an interactive web tool which provides a unique opportunity to access personalised data reports on the physical and mental health needs of people with intellectual disability in your LHD/SHN.

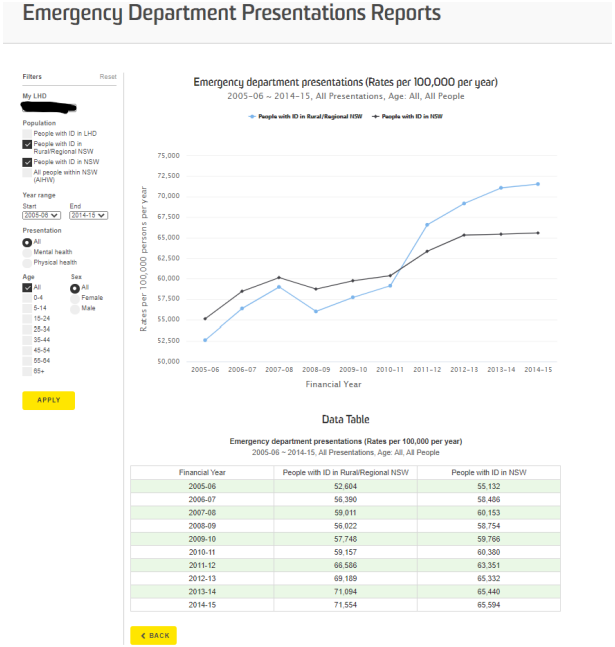
ID Health Data Portal



Reports will provide you with a regional profile of the:

- demographics,
- health profile,
- health service use, and
- associated costs for people with intellectual disability.

ID Health Data Portal



Each of the reports allows you to compare data from your LHD/SHN to others in NSW

Reports can be filtered by

- population,
- year range,
- age,
- sex and
- presentation type.

IDMH e-Learning for health professionals

About intellectual disability

- Introduction to intellectual disability
- Living with an intellectual disability
- Intellectual disability – Changing perspectives

Fundamental skills in IDMH

- Communication: The basics
- Improving your communication
- Equality in mental health care
- Consent, decision-making & privacy

Clinical foundations in IDMH

- Mental disorders in intellectual disability
- Assessment of mental disorders in intellectual disability
- Management of mental disorders in intellectual disability

Specialist topics in IDMH

- Challenging behaviour I – Introduction
- Challenging behaviour II – Assessment
- Challenging behaviour III – Management
- Emergency mental health care I – Understanding ID in the ED
- Emergency mental health care II – Journey through the ED

Cardiometabolic health

- Cardiometabolic health in people with intellectual disability – Understanding risk
- Cardiometabolic health in people with intellectual disability – Screening and intervention strategies

IDMH e-Learning for disability professionals

IDMH introduction

- Why is it important to know about mental health?
- Introduction to mental health
- Mental illness in intellectual disability

IDMH practical skills

- A person-centred approach
- Recognising common mental illness
- How to support a person with a possible mental illness and intellectual disability
- Supporting behaviours of concern

IDMH advanced topics

- Enhancing interagency working with health professionals
- Treatments and supports for mental illness
- How to support a person in a mental health crisis
- Supporting carers, colleagues and self-care

Specific disorders in IDMH

- Mental health in people with intellectual disability and autism spectrum disorder
- Personality disorders in intellectual disability

Psychological support through difficult situations

- Supporting people with intellectual disability at risk of self-harm and suicide
- Identifying and responding to abuse of people with intellectual disability

Supporting mental wellbeing

- Supporting good mental health in people with intellectual disability

Supporting mental health through the life course

- Supporting people with intellectual disability to understand and cope with death and dying
- Engaging people with intellectual disability in end-of-life discussions and providing support at the end of life
- Providing mental health support to people with intellectual disability through transitions and life events

IDMH e-Learning for carers and family

Foundations

- About intellectual disability
- About mental health

Mental health and illness

- Mental illness and intellectual disability
- Detecting changes in mental health and wellbeing

Specific mental illnesses

- Signs and symptoms of mood disorders
- Signs and symptoms of anxiety disorders
- Signs and symptoms of schizophrenia and other psychotic disorders
- Signs and symptoms of dementia

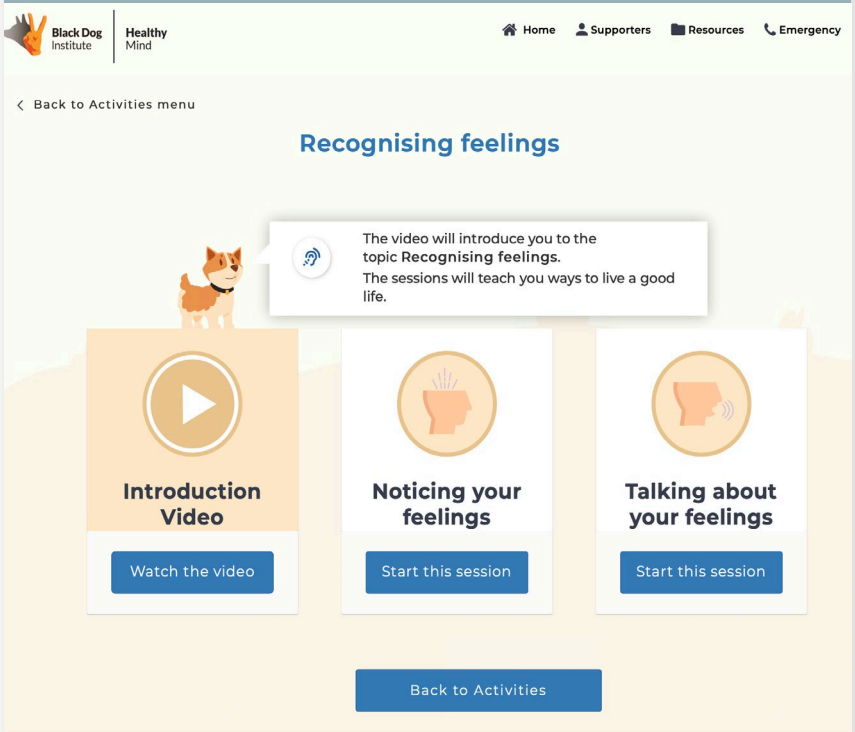
IDMH e-Learning – healthy lifestyle interventions

Adapting healthy lifestyle interventions for people with intellectual disability

- What is intellectual disability?
- Understanding health challenges and barriers to healthy lifestyle participation
- Making practical adjustments to healthy lifestyle design and delivery
- Working collaboratively and managing challenging behaviours
- Tailored teaching resources

Healthy Mind and IDTWO Study

Website



Website Details

- **Free** to all Australians
- 5 **mental health activities**
- **EasyRead** and audio prompts
- **Explainer videos** for all activities

healthymind.org.au

IDTWO Study Details

- Paid study for Australians 16 and over with ID
- Help us evaluate Healthy Mind!
- Help us understand how people with ID navigate digital health!

idtwo@blackdog.org.au

Black Dog Institute | UNSW Australia | 3DN Department of Developmental Disability Neuropsychiatry

Conclusions

- Providing appropriate mental health care to a person with an intellectual disability means
  - Responding to the barriers experienced by people with intellectual disability
  - Working in partnership with people with disability and their supporters, using a person centred approach
  - Understanding the vulnerability to mental illness
  - Understanding the assessment and drivers of behavioural changes
  - Developing knowledge and skills in mental health assessment and treatment
  - Being aware of resources that assist development of clinical skills and knowledge