

# Assessment and diagnosis

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## Key points

- It is important to take a longitudinal approach to assessment.
- Consider how you can meet the communication, sensory and physical needs of the person with intellectual disability during the assessment process.
- Establish baseline functioning to gain a better perspective on the presenting problems.
- Behavioural changes can be a result of mental or physical health.
- Seek collateral information from carers, family, support workers and health and disability professionals.
- Standard diagnosis criteria may not consider atypical or behavioural manifestations of mental illness for people with intellectual disability.
- Tentative or provisional diagnoses may be required, and diagnosis is often an ongoing process.

This section provides key information around working with people with intellectual disability during the assessment and diagnosis stage. Assessments are carried out to i) gather information to inform the problem formulation, diagnosis, and care plan ii) build rapport with the person (which is particularly important for people with intellectual disability and can take longer), and iii) record information to create a baseline to assess the impact of any interventions. The assessment findings inform the diagnosis (or provisional diagnosis), treatment approaches, behaviour support plans, and applications for additional support. Considerations for specific service types are provided at the end.

You may also like to view [3DN's Intellectual Disability Health Education](#) course [Assessment of Mental Disorders in Intellectual Disability](#) for a small fee or which is available free of charge for NSW Health professionals through [My Health Learning](#) on HETI.

Below are **key considerations** and **key questions** you may have when working with people with intellectual disability during the assessment and diagnosis stage.

For a list of specialist health services for people with intellectual disability see [Specialist intellectual disability services](#).

# Assessment

## Assessment – Key considerations

### Meeting the needs of people with intellectual disability before and during mental health assessments

There are several key considerations before and during an assessment to ensure the needs of people with intellectual disability are met.

First and foremost is to take a longitudinal approach to assessment. More time is required as information generally needs to be gathered from multiple sources (i.e. the individual, their support networks, other health, and disability professionals). Additional key considerations are below.



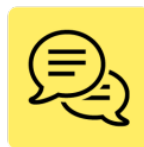
## Meeting the needs of people with intellectual disability during mental health assessment



Find out if someone will be accompanying the person



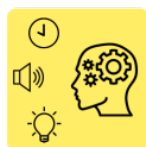
Ask the person to bring any relevant documents



Establish the person's communication needs



Consider a pre-appointment



Choose an appropriate assessment environment



Minimise anxiety in waiting rooms



Use picture cards to help people understand what will happen



Find out if the person has a guardian who makes health decisions for them

- Find out if someone will be accompanying the person to their appointment and their relationship to the person.
- Ask the person with intellectual disability or the person who will be accompanying them to bring the results of any relevant assessments/reports, monitoring charts, and behaviour support plans.
- Establish the person's communication needs and ensure information is accessible. See the [Communication](#) section for more information. See 3DN's [Making mental health information accessible for people with intellectual disability – A Toolkit](#) for more information.
- A pre-appointment may be beneficial to i) meet the person and show them around the e.g. clinic/office to help reduce anxiety and ii) understand more about the person's strengths to utilise in a strengths-based approach.
- Choose an appropriate assessment environment where

possible that addresses the person's physical and sensory needs.

- Many people with intellectual disability experience anxiety in waiting rooms. Suggest booking an appointment at a time when there is less likely to be a wait and endeavour to be on time. Ensure there is a quiet space for the person to wait rather than a busy waiting room. You could also let them know they can wait outside or in the car and you will call them when ready.
- Picture cards can be used to help people understand what will happen when they receive support for their mental health, for example i) professionals they will see and what they do, ii) the physical environment e.g. waiting room, treatments, and iii) routine for people in inpatient settings (e.g. mealtimes/bedtime).
- If not already determined from the Intake stage, find out if the individual has a guardian or [person responsible](#) who makes health decisions for them and gather their contact details. Continue to assess capacity to consent and promote supported decision-making. See the [NSW Trustee & Guardian](#) website and their [Capacity Toolkit](#). There is also more information in 3DN's [Intellectual Disability Mental Health Core Competency Framework Toolkit](#) (page 29) and [Intellectual Disability Health Education](#) course [Consent, Decision-Making and Privacy – A Guide for Clinicians](#).

## Assessment – Key questions

**What are the key components of a mental health assessment for people with intellectual disability?**

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**What assessment tools are suitable for people with intellectual disability?**

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**How can I work effectively with support networks?**

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**What if I need specialist advice and consultation at the assessment stage?**

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# Diagnosis

## Diagnosis – Key

# considerations

## Diagnostic criteria and differences for people with intellectual disability

Diagnosis for people with intellectual disability can be more challenging as i) their baseline functioning is more likely to be unique, ii) symptoms of mental illness are more likely to be behavioural or atypical, and iii) they are more likely to be experiencing challenges in various domains. Consider the following points with regard to diagnostic criteria.

- Standard diagnostic criteria that rely on people verbally reporting symptoms can be used by people with a mild level of intellectual disability who have relatively well developed communication skills. [3]
- Standard diagnostic criteria i) do not consider atypical symptoms or behavioural manifestations of mental illness in people with intellectual disability, ii) may assume a certain level of development in e.g. social functioning which cannot be assumed for people with intellectual disability, and iii) may not be valid for people with severe intellectual disability, communication impairments or those who have an autism spectrum disorder.
- [The Diagnostic Manual – Intellectual Disability 2 \(DM-ID 2\)](#) and the Diagnostic criteria for psychiatric disorders for use with adults with learning disabilities (DC-LD) [4] have adapted the DSM-IV and ICD-10 criteria respectively for people with intellectual disability.
- Consider ways that the subjective experience of a mental illness may be expressed differently in someone



with intellectual disability.

- A diagnosis should consider that behaviour and cognitions that are thought to be due to mental illness may in fact be caused by pain, physical illness, medication side effects, stress, or are normal idiosyncratic behaviours or cognitions for that person.
- Provide feedback to the person with intellectual disability and their support networks on the assessment findings and possible or provisional diagnosis in an accessible way for all parties. Seek their thoughts on your interpretations and take these into consideration. Explain the reasoning for only providing a provisional diagnosis if applicable, and whether further assessment will take place.

## Diagnosis – Key questions

**Why has a person's behaviour changed?**



**What if I am uncertain about a diagnosis?**



**What can I do in the event of a clinical stalemate?**



# Considerations for specific services

**Primary care**



**Emergency departments**



**Inpatient services**



## Resources

- See a list developed by 3DN of [assessment](#)

[tools](#) suitable for use with people with intellectual disability.

- The [Council for Intellectual Disability](#) has [checklists](#) that help guide health professionals and administrative staff through reasonable adjustments they can offer before, during and after a health appointment to ensure they are accessible to people with intellectual disability. The checklists include links to Easy Read templates such as appointment letters and referrals.
- [3DN's Intellectual Disability Health Education](#) course [Assessment of Mental Disorders in Intellectual Disability](#)
- Tools to assess baseline functioning such as the [Wellbeing Record](#) which can be used by carers and supporters to record a person's baseline wellbeing and any changes that occur.
- Tools to record a person's health history
  - Council for Intellectual Disability's [My Health Matters folder](#).
  - [Admission 2 Discharge A2D Together Folder](#)
- [The Diagnostic Manual – Intellectual Disability 2 \(DM-ID 2\)](#) provides diagnostic criteria of mental disorders for people with intellectual disability to facilitate accurate diagnosis.
- The [Society for the Study of Behavioural Phenotypes](#) has a series of [Syndrome Sheets](#) with information on genetic, cognitive and

behavioural aspects of different syndromes that can cause intellectual disability.

- For information on supported decision-making and capacity to consent see
  - [NSW Trustee & Guardian – Supported decision-making](#) section which includes a [Capacity Toolkit](#).
  - 3DN's [Intellectual Disability Mental Health Core Competency Framework Toolkit](#) (page 29)
  - [3DN's Intellectual Disability Health Education course Consent, Decision-Making, and Privacy – A Guide for Clinicians](#).
- 3DN's [Making mental health information accessible for people with intellectual disability – A Toolkit](#)

## References





Treatment



Transfers of  
care



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