

# Assessment of mental health problems in people with learning disabilities

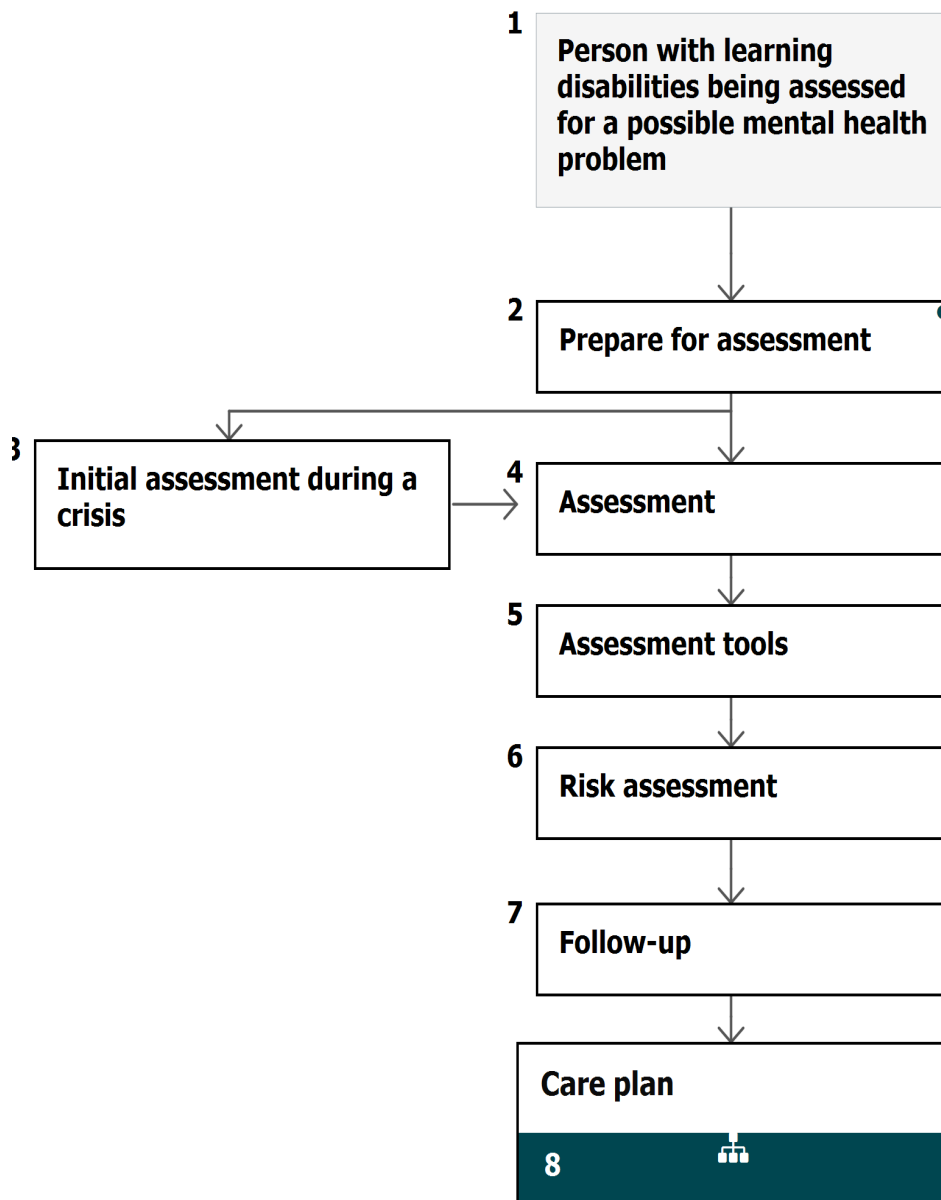
NICE Pathways bring together everything NICE says on a topic in an interactive flowchart. NICE Pathways are interactive and designed to be used online.

They are updated regularly as new NICE guidance is published. To view the latest version of this NICE Pathway see:

<http://pathways.nice.org.uk/pathways/mental-health-problems-in-people-with-learning-disabilities>

NICE Pathway last updated: 20 June 2018

This document contains a single flowchart and uses numbering to link the boxes to the associated recommendations.



## 1 Person with learning disabilities being assessed for a possible mental health problem

No additional information

## 2 Preparing the assessment

A professional with expertise in mental health problems in people with [learning disabilities](#) [See [page 9](#)] should coordinate the mental health assessment, and conduct it with:

- the person with the mental health problem, in a place familiar to them if possible, and help them to prepare for it if needed
- the family members, carers, care workers and others that the person wants involved in their assessment
- other professionals (if needed) who are competent in using a range of assessment tools and methods with people with learning disabilities and mental health problems.

Speak to the person on their own to find out if they have any concerns (including safeguarding concerns) that they don't want to talk about in front of their family members, carers or care workers.

Before mental health assessments:

- agree a clear objective, and explain it to the person, their family members, carers or care workers (as appropriate), and all professionals involved
- explain the nature and duration of the assessment to everyone involved
- explain the need to ask certain sensitive questions
- address any queries or concerns that the person may have about the assessment process.

### Quality standards

The following quality statement is relevant to this part of the interactive flowchart.

2. Assessment by a professional with relevant expertise

## 3 Initial assessment during a crisis

Conduct an initial assessment for people who are experiencing a mental health crisis, which

should:

- include an assessment of the person's mental health
- include a risk assessment
- include identification of interventions to:
  - help address the problem that caused the crisis
  - minimise any associated risks
  - bring stability to the individual and their immediate environment
- produce a crisis plan that sets out (using the least restrictive options possible) how to reduce the likelihood of further crises, and what to do if the person has another crisis.

## 4 Assessment

When conducting mental health assessments, be aware:

- that an underlying physical health condition may be causing the problem
- that a physical health condition, sensory or cognitive impairment may mask an underlying mental health problem
- that mental health problems can present differently in people with more severe learning disabilities [See page 9]

When conducting mental health assessments, take into account the person's:

- level of distress
- understanding of the problem
- living arrangements and settings where they receive care
- strengths and needs.

During mental health assessments:

- establish specific areas of need to focus on
- assess all potential psychopathology, and not just the symptoms and signs that the person and their family members, carers or care workers first report
- describe the nature, duration and severity of the presenting mental health problem
- take into account the person's cultural, ethnic and religious background
- review psychiatric and medical history, past treatments and response
- review physical health problems and any current medication, and refer to other specialists for review if needed
- review the nature and degree of the learning disabilities [See page 9], and if relevant the

- person's developmental history
- assess for problems that may be associated with particular behavioural phenotypes (for example, anxiety in people with autism and psychosis in people with Prader–Willi syndrome), so that they can be treated
- assess the person's family and social circumstances and environment, and recent life events
- assess the level of drug or alcohol use as a potential problem in itself and as a factor contributing to other mental health problems (see also what NICE says on [alcohol-use disorders](#), [drug misuse prevention](#), [drug misuse management in over 16s](#) and [coexisting severe mental illness and substance misuse: community health and social care services](#).)
- establish or review a diagnosis using:
  - a classification system such as DSM-5 or ICD-10, or those adapted for learning disabilities (for example the Diagnostic Manual – Intellectual Disability [DM-ID] or Diagnostic Criteria for Psychiatric Disorders for Use with Adults with Learning Disabilities/Mental Retardation [DC-LD]) **or**
  - problem specification
- assess whether a risk assessment is needed (see [risk assessment \[See page 6\]](#)).

Assess recent changes in behaviour using information from family members, carers, staff or others involved in the assessment as well as information from relevant records and previous assessments. Take into account the nature, quality and length of their relationship with the person.

Use the results of the mental health assessment to develop a written statement (formulation) of the mental health problem, which should form the basis of the care plan (see [care plan](#)) and cover:

- an understanding of the nature of the problem and its development
- precipitating and maintaining factors
- any protective factors
- the potential benefits, side effects and harms of any interventions
- the potential difficulties with delivering interventions
- the adjustments needed to deliver interventions
- the impact of the mental health problem and associated risk factors on providing care and treatment.

## 5 Assessment tools

During any mental health assessment:

- consider using tools that have been developed or adapted for people with learning disabilities [See page 9] **and**
- take cost into account if more than one suitable tool is available.

If using tools that have not been developed or adapted for people with learning disabilities, take this into account when interpreting the results.

When conducting an assessment with a child or young person with learning disabilities, consider using tools such as the Developmental Behavior Checklist – parent version (DBC-P) or the Strengths and Difficulties Questionnaire (SDQ).

When assessing depressive symptoms in an adult with learning disabilities, consider using a formal measure of depression to monitor change over time, such as the Glasgow Depression Scale (the self-report for people with milder learning disabilities [See page 9] or the carer supplement for people with any degree of learning disabilities).

See also what NICE says on depression.

Consider supplementing an assessment of dementia with an adult with learning disabilities with:

- measures of symptoms, such as the Dementia Questionnaire for People with Learning Disabilities (DLD), the Down Syndrome Dementia Scale (DSDS) or the Dementia Screening Questionnaire for Individuals with Intellectual Disabilities (DSQIID)
- measures of cognitive function to monitor changes over time, such as the Test for Severe Impairment (TSI)
- measures of adaptive function to monitor changes over time.

Complete a baseline assessment of adaptive behaviour with all adults with Down's syndrome.

See also what NICE says on dementia.

## 6 Risk assessment

When conducting risk assessments with people with learning disabilities [See page 9] and mental health problems, assess:

- risk to self
- risk to others (including sexual offending)
- risk of self-neglect
- vulnerability to exploitation

- likelihood and severity of any particular risk
- potential triggers, causal or maintaining factors
- whether safeguarding protocols should be implemented.

If indicated by the risk assessment, develop a risk management plan with the person and their family members, carers or care workers (as appropriate).

Risk management plans should:

- set out individual, social or environmental interventions to reduce risk
- be communicated to family members, carers or care workers (as appropriate) and all relevant staff and agencies.

Risk assessments and resulting risk management plans should be reviewed regularly and adjusted if risk levels change.

## 7 Follow-up

Provide the person, their family members, carers or care workers (as appropriate), and all relevant professionals with a summary of the assessment:

- in an agreed format and language
- that sets out the implications for care and treatment.

Give the person and their family members, carers or care workers (as appropriate) another chance to discuss the assessment after it has finished, for example at a follow-up appointment.

### Further assessment

Consider conducting a further assessment that covers any areas not explored by the initial assessment, if:

- new information emerges about the person's mental health problem **or**
- there are significant differences between the views of the person and the views of their family members, carers, care workers or staff about the problems that the assessment has focused on.

## 8 Care plan

[See Mental health problems in people with learning disabilities / Mental health problems in](#)

people with learning disabilities overview / Care plan



Learning disabilities are commonly divided into 'mild', 'moderate', 'severe' and 'profound', but these categories are based on IQ and most UK health and social care services do not measure this. Therefore, this guideline uses the terms 'milder learning disabilities' (approximating to mild and moderate learning disabilities) and 'more severe learning disabilities' (approximating to severe and profound learning disabilities).

All people with learning disabilities:

- need additional support at school
- need support in some areas of adult life, such as budgeting, planning, time management, and understanding complex information
- need more time to learn new skills than people who don't have learning disabilities.

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People with milder learning disabilities:

- may be able to live independently and care for themselves, managing everyday tasks and working in paid employment
- can communicate their needs and wishes
- may have some language skills
- may have needs that are not clear to people who do not know them well.

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or below with impairment of adaptive functioning and onset in childhood).

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- need more time to learn new skills than people who don't have learning disabilities.

People with more severe learning disabilities are more likely to:

- need support with daily activities such as dressing, washing, food preparation, and safety
- have limited or no verbal communication skills or understanding of others
- need support with mobility
- have complex health needs and sensory impairments.

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## Glossary

### Carer

a person who provides unpaid support to someone who is ill, having trouble coping or has disabilities; this does not include care workers (paid carers), who are included in the definition of staff

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### **Care pathways**

a care pathway is defined in this guideline as the ways different services interact with each other, and how people access and move between them

### **Care worker**

a person who provides paid support to someone who is ill, having trouble coping or has disabilities in a variety of settings (including residential homes, supported living settings and day services)

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### **Children**

aged 0–12 years

### **Key worker**

a key worker (also known as a care or case coordinator) is a central point of contact for the person with a mental health problem, family members, carers and the services involved in their care; they are responsible for helping the person and family members or carers to access services and for coordinating the involvement of different services – they ensure clear communication between all people and services and have an overall view of the person's needs and the requirements of their care plan

### **Serious mental illness**

is defined in this guideline as: severe and incapacitating depression or anxiety, psychosis, schizophrenia, bipolar disorder or schizoaffective disorder

### **Staff**

healthcare professionals and social care practitioners, including those working in community

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teams for adults, children or young people (such as psychologists, psychiatrists, social workers, speech and language therapists, nurses, behavioural analysts, occupational therapists, physiotherapists and pharmacists); and educational staff

## Young people

aged 13–17 years

## Sources

Mental health problems in people with learning disabilities: prevention, assessment and management (2016) NICE guideline NG54

## Your responsibility

### Guidelines

The recommendations in this guideline represent the view of NICE, arrived at after careful consideration of the evidence available. When exercising their judgement, professionals and practitioners are expected to take this guideline fully into account, alongside the individual needs, preferences and values of their patients or the people using their service. It is not mandatory to apply the recommendations, and the guideline does not override the responsibility to make decisions appropriate to the circumstances of the individual, in consultation with them and their families and carers or guardian.

Local commissioners and providers of healthcare have a responsibility to enable the guideline to be applied when individual professionals and people using services wish to use it. They should do so in the context of local and national priorities for funding and developing services, and in light of their duties to have due regard to the need to eliminate unlawful discrimination, to advance equality of opportunity and to reduce health inequalities. Nothing in this guideline should be interpreted in a way that would be inconsistent with complying with those duties.

Commissioners and providers have a responsibility to promote an environmentally sustainable health and care system and should assess and reduce the environmental impact of implementing NICE recommendations wherever possible.

## Technology appraisals

The recommendations in this interactive flowchart represent the view of NICE, arrived at after careful consideration of the evidence available. When exercising their judgement, health professionals are expected to take these recommendations fully into account, alongside the individual needs, preferences and values of their patients. The application of the recommendations in this interactive flowchart is at the discretion of health professionals and their individual patients and do not override the responsibility of healthcare professionals to make decisions appropriate to the circumstances of the individual patient, in consultation with the patient and/or their carer or guardian.

Commissioners and/or providers have a responsibility to provide the funding required to enable the recommendations to be applied when individual health professionals and their patients wish to use it, in accordance with the NHS Constitution. They should do so in light of their duties to have due regard to the need to eliminate unlawful discrimination, to advance equality of opportunity and to reduce health inequalities.

Commissioners and providers have a responsibility to promote an environmentally sustainable health and care system and should assess and reduce the environmental impact of implementing NICE recommendations wherever possible.

## Medical technologies guidance, diagnostics guidance and interventional procedures guidance

The recommendations in this interactive flowchart represent the view of NICE, arrived at after careful consideration of the evidence available. When exercising their judgement, healthcare professionals are expected to take these recommendations fully into account. However, the interactive flowchart does not override the individual responsibility of healthcare professionals to make decisions appropriate to the circumstances of the individual patient, in consultation with the patient and/or guardian or carer.

Commissioners and/or providers have a responsibility to implement the recommendations, in their local context, in light of their duties to have due regard to the need to eliminate unlawful discrimination, advance equality of opportunity, and foster good relations. Nothing in this interactive flowchart should be interpreted in a way that would be inconsistent with compliance with those duties.

Commissioners and providers have a responsibility to promote an environmentally sustainable health and care system and should assess and reduce the environmental impact of implementing NICE recommendations wherever possible.