

Mental health problems in people with learning disabilities overview

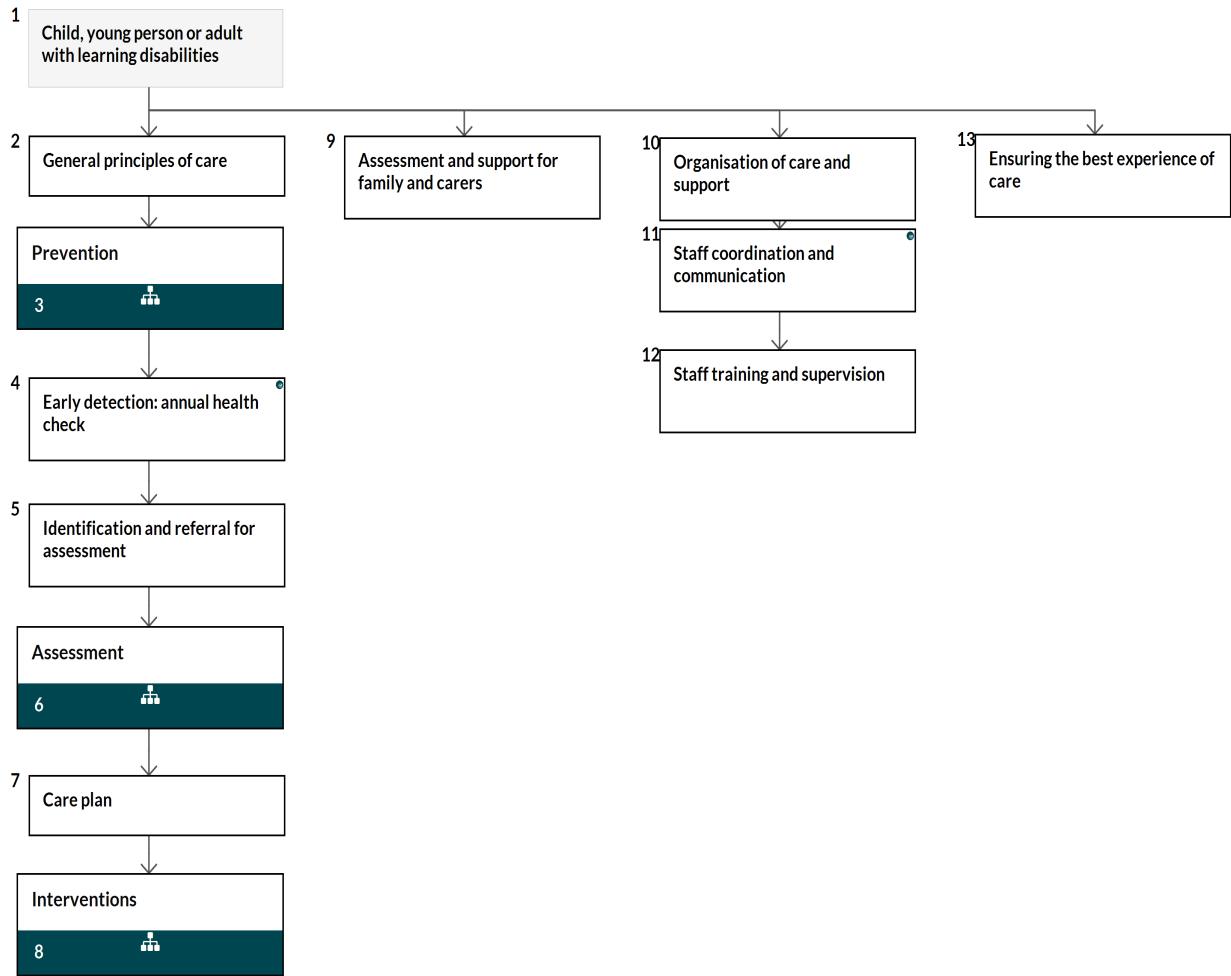
NICE Pathways bring together everything NICE says on a topic in an interactive flowchart. NICE Pathways are interactive and designed to be used online.

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: 15 July 2020

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



1 Child, young person or adult with learning disabilities

No additional information

2 General principles of care

Communication

Take into account the person's communication needs and level of understanding throughout assessments, treatment and care for a mental health problem, and:

- speak to the person directly rather than talking about or over them
- use clear, straightforward and unambiguous language
- assess whether communication aids, an advocate or someone familiar with the person's communication methods are needed
- make adjustments to accommodate sensory impairments (including sight and hearing impairments)
- explain the content and purpose of every meeting or session
- use concrete examples, visual imagery, practical demonstrations and role play to explain concepts
- communicate at a pace that is comfortable for the person, and arrange longer or additional meetings or treatment sessions if needed
- use different methods and formats for communication (written, signing, visual, verbal, or a combination of these), depending on the person's preferences (see [NHS England's Accessible Information Standard](#) for guidance on ensuring people with [learning disabilities](#) [[See page 12](#)] receive information in formats they can understand)
- regularly check the person's understanding
- summarise and explain the conclusions of every meeting or session
- check that the person has communicated what they wanted.

Consent, capacity and decision making

Assess the person's capacity to make decisions throughout assessment, care and treatment for the mental health problem on a decision-by-decision basis, in accordance with the Mental Capacity Act and supporting codes of practice (see [NICE's information on making decisions about your care](#)). Help people make decisions by ensuring that their communication needs are met (see communication, above) and (if appropriate) involving a family member, carer, care worker or other individual familiar with the person's communication abilities.

Staff delivering care to people with learning disabilities and mental health problems should:

- discuss the assessment process and treatment options with the person and provide information in a format and language suited to their needs, including
 - potential benefits
 - potential side effects or disadvantages
 - the purpose of treatment
 - outcome measures
- ensure that the person understands the purpose, plan and content of any meeting or intervention before it starts, and regularly throughout
- address any queries or concerns that the person may have at any stage
- allow enough time for the person to make an informed choice if they have decision-making capacity, and if they do not then provide enough time for their family members, carers or care workers to contribute fully.

Involving the family and carers

Encourage and support family members, carers and care workers (as appropriate) to be actively involved throughout the assessment, care and treatment of the person's mental health problem, apart from in exceptional circumstances when an adult or young person with decision-making capacity has said that they do not want them involved.

Give family members, carers and care workers (as appropriate) information about support and interventions in a suitable format and language, including [NICE's information for the public](#).

Interventions

Use these recommendations with NICE's recommendations on specific mental health problems, and take into account:

- differences in the presentation of mental health problems
- communication needs
- decision-making capacity
- the degree of learning disabilities
- the treatment setting (for example, primary or secondary care services, mental health or learning disabilities services, in the community or the person's home)
- interventions specifically for people with learning disabilities (see [prevention](#), and [interventions](#)).

When to suspect child maltreatment

See [the NICE Pathway on child abuse and neglect](#).

3 Prevention

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

4 Early detection: annual health check

GPs should offer an annual health check using a standardised template to all adults with learning disabilities, and all children and young people with learning disabilities who are not having annual health checks with a paediatrician.

Involve a family member, carer or care worker (as appropriate), or a healthcare professional or social care practitioner who knows the person well, in the annual health check. Take into account that more time may be needed to complete health checks with people with learning disabilities.

Include the following in annual health checks:

- a mental health review, including any known or suspected mental health problems and how they may be linked to any physical health problems
- a physical health review, including assessment for the conditions and impairments which are common in people with learning disabilities
- a review of all current interventions, including medication and related side effects, adverse events, interactions and adherence
- an agreed and shared care plan for managing any physical health problems (including pain).

During annual health checks with adults with Down's syndrome, ask them and their family members, carers or care workers (as appropriate) about any changes that might suggest the need for an assessment of dementia, such as:

- any change in the person's behaviour
- any loss of skills (including self-care)
- a need for more prompting in the past few months.

Hearing assessments

Consider referring people with a diagnosed learning disability to an audiology service for a hearing assessment when they transfer from child to adult services, and then every 2 years.

See [the NICE Pathway on hearing loss](#).

Quality standards

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

1. Annual health check

5 Identification and referral for assessment

Staff and others caring for people with learning disabilities should consider a mental health problem if a person with [learning disabilities \[See page 12\]](#) shows any changes in behaviour, for example:

- loss of skills or needing more prompting to use skills
- social withdrawal
- irritability
- avoidance
- agitation
- loss of interest in activities they usually enjoy.

Staff should consider using identification questions (adjusted as needed) as recommended in the NICE Pathways on specific mental health problems to identify common mental health problems in people with learning disabilities.

Paediatricians should explain to parents of children identified with learning disabilities that mental health problems are common in people with learning disabilities, and may present in different ways.

If a mental health problem is suspected in a person with learning disabilities, staff should conduct a triage assessment to establish an initial formulation of the problem. This should include:

- a description of the problem, including its nature, severity and duration

- an action plan including possible referral for further assessment and interventions.

Refer people with learning disabilities who have a suspected serious mental illness or suspected dementia to a psychiatrist with expertise in assessing and treating mental health problems in people with learning disabilities.

See also [the NICE Pathway on dementia](#).

6 Assessment

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

7 Care plan

Develop a mental health care plan with each person with [learning disabilities](#) [See page 12] and a mental health problem and their family members, carers or care workers (as appropriate), and integrate it into their other care plans.

Base mental health care plans on the written statement (formulation) and include in them:

- goals agreed with the person and the steps to achieve them
- treatment decisions
- agreed outcome measures that are realistic and meaningful to the person, to monitor progress
- early warning signs of relapse or exacerbation of symptoms, if known
- risk and crisis plans, if needed
- steps to minimise future problems.

Ensure that the mental health care plan sets out the roles and responsibilities of everyone involved in delivering it, and that:

- the person can easily access all interventions and services in the plan
- it is communicated to everyone involved, including the person and their family members, carers or care workers (as appropriate)
- there is an agreement on when the plan will be reviewed.

See also [the NICE Pathways on multimorbidity](#) and [transition between community or care home](#)

and inpatient mental health settings.

8 Interventions

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

9 Assessment and support for family and carers

Advise family members and carers about their right to carer assessment, and assessment for respite care and other support (see [the NICE Pathway on supporting adult carers](#) for recommendations on identifying, assessing and meeting the caring, physical and mental health needs of families and carers).

When providing support to family members (including siblings) and carers:

- recognise the potential impact of living with or caring for a person with [learning disabilities](#) [[See page 12](#)] and a mental health problem
- explain how to access:
 - family advocacy
 - family support and information groups
 - disability-specific support groups for family members or carers
- provide skills training and emotional support, or information about how to access these, to help them take part in and support interventions for the person with learning disabilities and a mental health problem.

If a family member or carer also has an identified mental health problem, offer:

- interventions in line with NICE's recommendations on specific mental health problems **or**
- referral to a mental health professional who can provide interventions in line with NICE guidance.

10 Organisation of care and support

A designated leadership team of healthcare professionals, educational staff, social care practitioners and health and local authority commissioners should develop and implement service delivery systems in partnership with people with [learning disabilities](#) [[See page 12](#)] and

mental health problems and (as appropriate) their family members, carers, self-advocates or care workers.

The designated leadership team should ensure that care is:

- person-centred and integrated within a care programme
- negotiable, workable and understandable for people with learning disabilities and mental health problems, their family members, carers or care workers, and staff
- accessible and acceptable to people using the services
- responsive to the needs and abilities of people with learning disabilities, and that reasonable adjustments (in line with the [Equality Act 2010](#)) are made if needed
- regularly audited to assess effectiveness, accessibility and acceptability.

The designated leadership team should ensure that care pathways:

- cover all health, social care, support and education services, and define the roles and responsibilities of each service
- have designated staff who are responsible for coordinating:
 - how people are involved with a care pathway
 - transition between services within and across different care pathways
- maintain consistency of care
- have protocols for sharing information:
 - with the person with learning disabilities and a mental health problem and their family members, carers or care workers (as appropriate)
 - with other staff (including GPs) involved in the person's care
- are focused on outcomes (including measures of quality, service user experience and harm)
- establish clear links (including access and entry points) to other care pathways (including those for physical health problems).

The designated leadership team should ensure that young people with learning disabilities and mental health problems have in place plans that address their health, social, educational and recreational needs (including Education, Health and Care plans), as part of their transition to adult services and adulthood. This planning should start when young people are aged 14 and follow [the NICE Pathway on transition from children's to adults' services](#).

The designated leadership team, together with health and social care providers, should ensure that care pathways:

- provide access to all NICE-recommended interventions for mental health problems

- clearly state the responsibilities of specialist learning disabilities and specialist mental health services to ensure people's needs are met.

For people with learning disabilities who need acute inpatient treatment for a serious mental illness, provide treatment:

- within a locally available service where possible and
- with staff who are skilled and knowledgeable in the care and treatment of mental health problems in people with learning disabilities.

11 Staff coordination and communication

Staff working with people with [learning disabilities](#) [See page 12] and mental health problems should ensure they are fully informed about:

- the nature and degree of the learning disabilities
- the nature and severity of the mental health problem, and any physical health problems (including sensory impairments).

All people with learning disabilities and a serious mental illness should have a key worker who:

- coordinates all aspects of care, including safeguarding concerns and risk management
- helps services communicate with the person and their family members, carers or care workers (as appropriate) clearly and promptly, in a format and language suited to the person's needs and preferences
- monitors the implementation of the care plan and its outcomes.

Quality standards

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

3. Key worker

12 Staff training and supervision

Health, social care and education services should train all staff who may come into contact with people with [learning disabilities](#) [See page 12] to be aware:

- that people with learning disabilities are at increased risk of mental health problems
- that mental health problems may develop and present in different ways from people without

- learning disabilities, and the usual signs or symptoms may not be observable or reported
- that people with learning disabilities can develop mental health problems for the same reasons as people without learning disabilities (for example, because of financial worries, bereavement or relationship difficulties)
- that mental health problems are commonly overlooked in people with learning disabilities
- where to refer people with learning disabilities and suspected mental health problems.

Health and social care services should ensure that staff who deliver interventions for people with learning disabilities and mental health problems are competent, and that they:

- receive regular high-quality supervision
- deliver interventions based on relevant manuals, if available
- evaluate adherence to interventions
- take part in the monitoring of their practice (for example, by using video and audio recording, external audit and scrutiny).

Health and social care staff who deliver interventions for people with learning disabilities and mental health problems should consider using routine sessional outcome measures, including service-user-reported experience measures.

13 Experience of care

Use these recommendations together with the recommendations in the NICE Pathways on:

- [patient experience in adult NHS services](#)
- [people's experience in adult social care services](#)
- [service user experience in adult mental health services](#)
- [learning disabilities and behaviour that challenges](#), if relevant.

See also the recommendations for improving the experience of care for children and young people in the NICE Pathways on specific mental health problems.

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.

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)

Carers

(people who provide 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)

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))

Care workers

(people who provide 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))

Children

(aged 0 to 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 guidance 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 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 to 17 years)

Sources

[Hearing loss in adults: assessment and management \(2018\) NICE guideline NG98](#)

[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.