NICE National Institute for Health and Care Excellence

NICE guideline

Mental health problems in people with learning disabilities: prevention, assessment and management

NICE guideline

Published: 14 September 2016
nice.org.uk/guidance/ng54

Your responsibility

The recommendations in this guideline represent the view of NICE, arrived at after careful consideration of the evidence available. When exercising their judgement, professionals are expected to take this guideline fully into account, alongside the individual needs, preferences and values of their patients or service users. The application of the recommendations in this guideline are not mandatory and the guideline does 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.

Local commissioners and/or providers have a responsibility to enable the guideline to be applied when individual health professionals and their patients or service users 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 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.

Contents

This guideline partially replaces CG42.

This guideline is the basis of QS142.

Overview

This guideline covers preventing, assessing and managing mental health problems in people with learning disabilities in all settings (including health, social care, education, and forensic and criminal justice). It aims to improve assessment and support for mental health conditions, and help people with learning disabilities and their families and carers to be involved in their care.

Who is it for?

- Healthcare professionals
- Social care practitioners
- Care workers
- Education staff
- Commissioners and service providers
- People with learning disabilities and their families and carers

Recommendations

People have the right to be involved in discussions and make informed decisions about their care, as described in your care.

Making decisions using NICE guidelines explains how we use words to show the strength of our recommendations, and has information about safeguarding, consent and prescribing medicines (including 'off-label' use).

1.1 Using this guideline with other NICE guidelines

Improving the experience of care

1.1.1 Use this guideline with:

- the NICE guidelines on service user experience in adult mental health and patient experience in adult NHS services, to improve the experience of care for adults with learning disabilities and mental health problems
- recommendations for improving the experience of care for children and young people in the NICE guidelines on specific mental health problems
- the NICE guideline on challenging behaviour and learning disabilities if relevant.

Interventions for mental health problems in people with learning disabilities

1.1.2 Use this guideline with the NICE guidelines on specific mental health problems, and take into account:

- differences in the presentation of mental health problems
- communication needs (see recommendation 1.3.1)
- decision-making capacity (see recommendation 1.3.2)
- 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 section 1.5 and sections 1.9 to 1.11).

1.2 Organisation and delivery of care and support

Organising effective care

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

1.2.2 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.

1.2.3 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).

1.2.4 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 guideline on transition from children's to adults' services.

1.2.5 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.

1.2.6 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.

Staff coordination and communication

1.2.7 Staff working with people with learning disabilities 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).

1.2.8 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.

Staff training and supervision

1.2.9 Health, social care and education services should train all staff who may come into contact with people with learning disabilities 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.

1.2.10 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).

1.2.11 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.

1.3 Involving people with learning disabilities, and their family members, carers or care workers, in mental health assessment and treatment

Communication

1.3.1 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 the Accessible Information Standard for guidance on ensuring people with learning disabilities 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

1.3.2 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 your care). Help people make decisions by ensuring that their communication needs are met (see recommendation 1.3.1) and (if appropriate) involving a family member, carer, care worker or other individual familiar with the person's communication abilities.

1.3.3 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 family members, carers and care workers

1.3.4 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.

1.3.5 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.

1.4 Support and interventions for family members and carers

1.4.1 Advise family members and carers about their right to the following and how to get them:

- a formal assessment of their own needs (known as a 'Carer's Assessment'), including their physical and mental health
- short breaks and other respite care.

1.4.2 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 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.

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

- interventions in line with the NICE guidelines on specific mental health problems **or**
- referral to a mental health professional who can provide interventions in line with NICE guidelines.

1.5 Social and physical environment interventions

1.5.1 Health, social care and education services should consider the impact of the social and physical environment on the mental health of children and young people with learning disabilities when developing care plans, and:

- provide positive educational environments that are appropriate to their needs
- when care placements (such as birth family to foster care, foster care to adoptive placement, home to residential school/college) are required, minimise the risk of placement breakdown by taking particular care to fit these to the needs of the person.
- give special consideration and support to looked-after children and young people with learning disabilities and their foster parents or care workers, to reduce the child or young person's very high risk of developing mental health problems, and the risk of changes in their home and carers (see the NICE guideline on looked-after children and young people).

1.5.2 Health, social care and education services should consider the impact of the social and physical environment on the mental health of adults with learning disabilities when developing care plans,and:

- support people to live where and with whom they want
- encourage family involvement in the person's life, if appropriate
- support people to get involved in activities that are interesting and meaningful to them
- plan for and help people with any significant changes to their living arrangements.

1.6 Annual health check

The following recommendations on annual health checks for people with learning disabilities build on recommendation 1.2.1 in the NICE guideline on challenging behaviour and learning disabilities, which relates to the provision of annual physical checks by GPs to all people with learning disabilities.

1.6.1 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.

1.6.2 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.

1.6.3 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).

1.6.4 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.

1.7 Identification and referral

1.7.1 Staff and others caring for people with learning disabilities should consider a mental health problem if a person with learning disabilities 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.

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

1.7.3 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.

1.7.4 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.

1.7.5 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.

1.8 Assessment

Conducting a mental health assessment

1.8.1 A professional with expertise in mental health problems in people with learning disabilities 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.

1.8.2 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.

1.8.3 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.

1.8.4 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.

1.8.5 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.

1.8.6 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, 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
- 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 recommendation 1.8.18).

1.8.7 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.

1.8.8 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 recommendation 1.8.23) 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.

1.8.9 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.

1.8.10 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

1.8.11 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.

Assessment tools

1.8.12 During any mental health assessment:

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

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

1.8.14 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).

1.8.15 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 or the carer supplement for people with any degree of learning disabilities).

1.8.16 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.

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

Risk assessment

1.8.18 When conducting risk assessments with people with learning disabilities 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.

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

1.8.20 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.

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

Mental health assessment during a crisis

1.8.22 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 (see recommendations 1.8.18–1.8.21)
- 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.

The mental health care plan

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

1.8.24 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 (see recommendations 1.8.18–1.8.22)
- steps to minimise future problems.

1.8.25 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.

1.9 Psychological interventions

Delivering psychological interventions for mental health problems in people with learning disabilities

1.9.1 For psychological interventions for mental health problems in people with learning disabilities, refer to the NICE guidelines on specific mental health problems and take into account:

- the principles for delivering psychological interventions (see recommendations 1.9.2–1.9.4) and
- the specific interventions recommended in this guideline (see recommendations 1.9.5–1.9.9).

1.9.2 Use the mental health assessment to inform the psychological intervention and any adaptations to it, and:

- tailor it to their preferences, level of understanding, and strengths and needs
- take into account any physical, neurological, cognitive or sensory impairments and communication needs
- take into account the person's need for privacy (particularly when offering interventions on an outreach basis)
- agree how it will be delivered (for example, face-to-face or remotely by phone or computer), taking into account the person's communication needs and how suitable remote working is for them.

1.9.3 If possible, collaborate with the person and their family members, carers or care workers (as appropriate) to:

- develop and agree the intervention goals
- develop an understanding of how the person expresses or describes emotions or distressing experiences
- agree the structure, frequency, duration and content of the intervention, including its timing, mode of delivery and pace

- agree the level of flexibility needed to effectively deliver the intervention
- agree how progress will be measured and how data will be collected (for example, visual representations of distress or wellbeing).

1.9.4 Be aware that people with learning disabilities might need more structured support to practise and apply new skills to everyday life between sessions. In discussion with the person, consider:

- providing additional support during meetings and in the planning of activities between meetings
- asking a family member, carer or care worker to provide support and assistance (such as reminders) to practise new skills between meetings.

Specific psychological interventions

1.9.5 Consider cognitive behavioural therapy, adapted for people with learning disabilities (see recommendation 1.9.2 on intervention adaptation methods), to treat depression or subthreshold depressive symptoms in people with milder learning disabilities.

1.9.6 Consider relaxation therapy to treat anxiety symptoms in people with learning disabilities.

1.9.7 Consider using graded exposure techniques to treat anxiety symptoms or phobias in people with learning disabilities.

1.9.8 Consider parent training programmes specifically designed for parents or carers of children with learning disabilities to help prevent or treat mental health problems in the child, and to support carer wellbeing.

1.9.9 Parent training programmes should:

- be delivered in groups of parents or carers
- be accessible (for example, take place outside normal working hours or in community settings with childcare facilities)
- focus on developing communication and social functioning skills

- typically consist of 8 to 12 sessions lasting 90 minutes
- follow the relevant treatment manual
- use all of the necessary materials to ensure consistent implementation of the programme
- seek parent feedback.

1.10 Pharmacological interventions

1.10.1 For pharmacological interventions for mental health problems in people with learning disabilities, refer to the NICE guidelines on specific mental health problems and take into account the principles for delivering pharmacological interventions (see recommendations 1.10.2–1.10.9).

1.10.2 For guidance on adherence and the safe and effective use of medicines, see the NICE guidelines on medicines adherence and optimisation.

1.10.3 Only specialists with expertise in treating mental health problems in people with learning disabilities should start medication to treat a mental health problem in:

- adults with more severe learning disabilities (unless there are locally agreed protocols for shared care)
- children and young people with any learning disabilities.

1.10.4 Before starting medication for a mental health problem in children, young people or adults with learning disabilities:

- take account of:
  - potential medication interactions
  - the potential impact of medication on other health conditions
  - the potential impact of other health conditions on the medication
- when necessary consult with specialists (for example, neurologists providing epilepsy care when prescribing antipsychotic medication that may lower the seizure threshold), to minimise possible interactions

- assess the risk of non-adherence to the medication regimen or any necessary monitoring tests (for example, blood tests), and the implications for treatment
- establish a review schedule to reduce polypharmacy
- provide support to improve adherence (see the NICE guideline on medicines adherence)
- assess whether support from community and learning disabilities nurses is needed for physical investigations (such as blood tests)
- agree monitoring responsibilities, including who will carry out blood tests and other investigations, between primary and secondary care.

1.10.5 Monitor and review the benefits and possible harms or side effects, using agreed outcome measures and taking into account communication needs. If stated in the relevant NICE guideline, use the timescales given for the specific disorder to inform the review, and adjust it to the person's needs.

1.10.6 When deciding the initial dose and subsequent increases, aim for the lowest effective dose. Take account of both potential side effects and difficulties the person may have in reporting them, and the need to avoid sub-therapeutic doses that may not treat the mental health problem effectively.

1.10.7 Prescribers should record:

- a summary of what information was provided about the medication prescribed, including side effects, to the person and their family members, carers or care workers (as appropriate) and any discussions about this
- when the medication will be reviewed
- plans for reducing or discontinuing the medication, if appropriate
- full details of all medication the person is taking, including the doses, frequency and purpose.

1.10.8 For people with learning disabilities who are taking antipsychotic drugs and not experiencing psychotic symptoms:

- consider reducing or discontinuing long-term prescriptions of antipsychotic drugs,

- review the person's condition after reducing or discontinuing a prescription
- consider referral to a psychiatrist experienced in working with people with learning disabilities and mental health problems
- annually document the reasons for continuing the prescription if it is not reduced or discontinued.

1.10.9 When switching medication, pay particular attention to discontinuation or interaction effects that may occur during titration. Only change one drug at a time, to make it easier to identify these effects.

1.11 Occupational interventions

1.11.1 In keeping with the preferences of the person with learning disabilities and mental health problems, all staff should support them to:

- engage in community activities, such as going to a library or sports centre
- access local community resources such as libraries, cinemas, cafes and leisure centres
- take part in leisure activities, such as hobbies, which are meaningful to the person.

  Reasonable adjustments may be needed to do this (in line with the Equality Act 2010), such as a buddy system, transport, or advising local facilities on accessibility.

1.11.2 Actively encourage adults with learning disabilities (with or without a mental health problem) to find and participate in paid or voluntary work that is meaningful to them, if they are able.

1.11.3 Consider providing practical support to adults with learning disabilities (with or without a mental health problem) to find paid or voluntary work, including:

- preparing a CV
- identifying personal strengths and interests
- completing application forms
- preparing for interviews
- accompanying the person to interviews

- completing any pre-employment checks.

1.11.4 Health and social care services should take account of an adult or young person's sensory, physical, cognitive and communication needs and the severity of their mental health problem (if any), and consider:

- helping them to identify and overcome any possible challenges during employment
- appointing supported employment workers to provide ongoing support to adults with learning disabilities and their employers
- providing information and guidance to potential employers about the benefits of recruiting people with learning disabilities
- assisting employers in making reasonable adjustments to help them to work (in line with the Equality Act 2010).

Terms used in this guideline

Carer

A person who provides unpaid support to someone who is ill, having trouble coping or has disabilities.

Care pathways

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).

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.

Learning disabilities

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 that are often defined as an IQ of 35–69 and impairment of adaptive functioning with onset in childhood) and 'more severe learning disabilities' (approximating to severe and profound learning disabilities that are often defined as an IQ of 34 or below with impairment of adaptive functioning with onset in childhood).

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.

Milder learning disabilities

People with milder learning disabilities:

- may be able to live independently and care for themselves, managing everyday tasks and working in paid employment
- can often 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.

More severe learning disabilities

People with more severe learning disabilities are more likely to:

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

Serious mental illness

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 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 education staff.

Young people

Aged 13–17 years.

Putting this guideline into practice

NICE has produced tools and resources to help you put this guideline into practice.

Putting recommendations into practice can take time. How long may vary from guideline to guideline, and depends on how much change in practice or services is needed. Implementing change is most effective when aligned with local priorities.

Changes recommended for clinical practice that can be done quickly – like changes in prescribing practice – should be shared quickly. This is because healthcare professionals should use guidelines to guide their work – as is required by professional regulating bodies such as the General Medical and Nursing and Midwifery Councils.

Changes should be implemented as soon as possible, unless there is a good reason for not doing so (for example, if it would be better value for money if a package of recommendations were all implemented at once).

Different organisations may need different approaches to implementation, depending on their size and function. Sometimes individual practitioners may be able to respond to recommendations to improve their practice more quickly than large organisations.

Here are some pointers to help organisations put NICE guidelines into practice:

1. **Raise awareness** through routine communication channels, such as email or newsletters, regular meetings, internal staff briefings and other communications with all relevant partner organisations. Identify things staff can include in their own practice straight away.

2. **Identify a lead** with an interest in the topic to champion the guideline and motivate others to support its use and make service changes, and to find out any significant issues locally.

3. **Carry out a baseline assessment** against the recommendations to find out whether there are gaps in current service provision.

4. **Think about what data you need to measure improvement** and plan how you will collect it. You may want to work with other health and social care organisations and specialist groups to compare current practice with the recommendations. This may also help identify local issues that will slow or prevent implementation.

5. **Develop an action plan**, with the steps needed to put the guideline into practice, and make sure it is ready as soon as possible. Big, complex changes may take longer to implement, but some may be quick and easy to do. An action plan will help in both cases.

6. **For very big changes** include milestones and a business case, which will set out additional costs, savings and possible areas for disinvestment. A small project group could develop the action plan. The group might include the guideline champion, a senior organisational sponsor, staff involved in the associated services, finance and information professionals.

7. **Implement the action plan** with oversight from the lead and the project group. Big projects may also need project management support.

8. **Review and monitor** how well the guideline is being implemented through the project group. Share progress with those involved in making improvements, as well as relevant boards and local partners.

NICE provides a comprehensive programme of support and resources to maximise uptake and use of evidence and guidance. See our into practice pages for more information.

Also see Leng G, Moore V, Abraham S, editors (2014) Achieving high quality care – practical experience from NICE. Chichester: Wiley.

Context

People of all ages with all levels of learning disabilities can be affected by mental health problems. When a person is not able to describe or express their distress, and when they have coexisting physical health problems, their mental health problems can be difficult to identify. This leads to mental health problems remaining unrecognised, which prolongs unnecessary distress. Psychosis, bipolar disorder, dementia, behaviour that challenges, and neurodevelopmental conditions such as autism and attention deficit hyperactivity disorder are all more common than in people without learning disabilities, and emotional disorders are at least as common. Some causes of learning disabilities are associated with particularly high levels of specific mental health problems (for example, affective psychosis in Prader–Willi syndrome and dementia in Down's syndrome).

When people with learning disabilities experience mental health problems, the symptoms are sometimes wrongly attributed to the learning disabilities or a physical health problem rather than a change in the person's mental health. Indeed, their physical health state can contribute to mental ill health, as can the degree and cause of their learning disabilities (including behavioural phenotypes), biological factors (such as pain and polypharmacy), psychological factors (such as trauma) and social factors (such as neglect, poverty and lack of social networks).

Population-based estimates suggest in the UK that 40% (28% if problem behaviours are excluded) of adults with learning disabilities experience mental health problems at any point in time. An estimated 36% (24% if problem behaviours are excluded) of children and young people with learning disabilities experience mental health problems at any point in time. These rates are much higher than for people who do not have learning disabilities.

This guideline covers the identification, assessment, treatment and prevention of mental health problems in children, young people and adults with any degree of learning disabilities. In addition, there are recommendations on support for family members, carers and care workers.

The guideline covers all settings (including health, social care, educational, forensic and criminal justice settings).

People with learning disabilities have many needs both as individuals and related to their learning disabilities. This guideline only addresses their needs in relation to mental health problems.

More information

You can also see this guideline in the NICE pathway on mental health problems in people with learning disabilities.

To find out what NICE has said on topics related to this guideline, see our web page on mental health and behavioural conditions.

See also the guideline committee's discussion and the evidence reviews (in the full guideline), and information about how the guideline was developed, including details of the committee.

Recommendations for research

The Guideline Committee has made the following recommendations for research. The Committee's full set of research recommendations is detailed in the full guideline.

1 Develop case identification tools for common mental health problems

Develop or adapt reliable and valid tools for the case identification of common mental health problems in people with learning disabilities, for routine use in primary care, social care and education settings.

Why this is important

Mental health problems are often overlooked and therefore untreated in people with learning disabilities. This includes common mental health problems such as depression and anxiety disorders, or dementia in Down's syndrome. As a result, the identification of mental health problems in people with learning disabilities was a priority for this guideline.

While case identification tools exist and are recommended for use in the general population, no suitable tools were found that help with initial identification for people with learning disabilities. Research to develop and validate such tools would be valuable when this guideline is updated. More reliable identification should help with early intervention and provide better outcomes, and earlier identification could also reduce costs for the NHS and social care. No relevant ongoing trials were identified.

Existing tools with the best psychometric properties could be adapted and validated for use with people with learning disabilities, or new tools could be developed that are appropriate for use. The tools should be readily available and useable in routine health, social care and education settings (such as by GPs or caregiving staff).

Tools should first be adapted or developed for the most common mental health problems within this population:

- dementia, depression and anxiety in adults
- depression and anxiety in children and young people.

A series of cohort studies are needed to validate the tools (new or existing). The studies could include the following outcomes:

- sensitivity and specificity
- predictive validity.

2 Psychological interventions for children and young people with internalising disorders

For children and young people with learning disabilities, what psychological interventions (such as cognitive behavioural therapy and interpersonal therapy) are clinically and cost effective for treating internalising disorders?

Why this is important

There is some evidence for the use of psychological interventions for internalising disorders in children and young people within the general population, and in adults with learning disabilities. However no evidence was found to indicate which interventions for internalising disorders are effective in children and young people with learning disabilities, or what adaptations are most helpful.

Psychological interventions commonly used within the general population (such as cognitive behavioural therapy and interpersonal therapy) should be adapted and tested in large randomised controlled trials. This research is crucial to improving the mental health outcomes in this population, and would have a significant impact upon updates of this guideline.

Important outcomes could include:

- effect on the mental health problem
- cost effectiveness
- health-related quality of life.

3 Psychological interventions for depression and anxiety disorders in adults with mild to moderate learning disabilities

For adults with milder learning disabilities, what is the clinical and cost effectiveness of psychological interventions such as cognitive behavioural therapy (modified for people with learning disabilities) for treating depression and anxiety disorders?

Why this is important

Psychological interventions such as cognitive behavioural therapy (CBT) are clinically and cost-effective treatments for anxiety and depression within the general population. While there is some evidence to suggest that these interventions may be useful in treating depression in people with learning disabilities, this is limited. Further research is also needed for CBT for anxiety disorders such as generalised anxiety disorder, obsessive compulsive disorder and post-traumatic stress disorder. The existing evidence on CBT for learning disabilities is based on small feasibility trials, with various and inconsistent adaptations across the studies. Many therapists are also reluctant to use CBT in this population. As a result, people with learning disabilities may be missing out on effective treatments. Effective treatments would reduce unnecessary suffering and impairment, improve quality of life and ultimately should reduce the demand for mental health and social care services.

Modifications of CBT need to be tested in large randomised controlled trials, and any modifications should be clearly explained and documented. In order to achieve an appropriate sample size, several different services may need to cooperate. Important outcomes could include:

- effect on the mental health problem
- cost effectiveness
- health-related quality of life.

4 Pharmacological interventions for anxiety disorders in people with learning disabilities who have autism

What is the clinical and cost effectiveness and safety of pharmacological interventions for anxiety disorders in people with learning disabilities who have autism?

Why this is important

Anxiety disorders are common in people with learning disabilities who have autism. However, there is no high-quality evidence on pharmacological interventions for anxiety disorders in people with learning disabilities who have autism. They may be more susceptible to adverse events, and have particular difficulty communicating side effects. There may also be differences in effectiveness compared with the general population. These uncertainties about side effects and effectiveness may contribute to the under-treatment of mental health problems in people with learning disabilities who have autism. Research is therefore needed to determine the safety and effectiveness of pharmacological interventions and make it clear what treatments are effective for

anxiety in people learning disabilities who have autism. Clarity over this issue could have a substantial impact upon quality of life for people with learning disabilities who have autism and their carers, as well as reducing costs to the NHS.

Randomised controlled trials should be carried out to compare the clinical and cost effectiveness of pharmacological interventions for anxiety disorders in this population. Several services may need to collaborate in order to ensure sufficient sample size. Researchers would need to take into account factors such as genotype and pharmacological treatment for other conditions when designing these trials. Important outcomes could include:

- effect on the mental health problem
- side effects
- cost effectiveness
- health-related quality of life.

5 Psychosocial interventions for people with more severe learning disabilities

For people with more severe learning disabilities, what is the clinical and cost effectiveness of psychosocial interventions to treat mental health problems?

Why this is important

People with more severe learning disabilities whose communication is non-verbal are likely to need tailored interventions to address mental health problems. Research is particularly limited on mental health problems in people with more severe learning disabilities. Further research is needed into different types of interventions, such as social interactions and building resilience. This research would fill a need within mental health services, which are currently limited in their ability to provide effective interventions to this group.

Randomised controlled trials should be carried out to compare the clinical and cost effectiveness of psychosocial interventions, which may include multiple components, to prevent and treat mental health problems in people with more severe learning disabilities. Several services may need to collaborate in order to ensure sufficient sample size. Important outcomes could include:

- effect on the mental health problem
- cost effectiveness

- health-related quality of life.

When designing these trials, appropriate measures will need to be developed for mental health problems in people with more severe learning disabilities.

6 The experiences of people with learning disabilities and mental health problems in services

What experience do people with learning disabilities have of services designed to prevent and treat mental health problems and how does this relate to clinical outcomes?

Why this is important

Mental health service provision for people with learning disabilities is complex and varies across the UK. There appears to be no high-quality evidence or ongoing research for any particular approach. Evidence on the experiences, aspirations and mental health of young people as they prepare for adulthood would help in the development of preventative strategies. Evidence on what service models are most effective and acceptable to people with learning disabilities would help to improve service design, staffing decisions and patient outcomes. This is also an area of national priority, as explained in the NHS Five Year Forward View.

To understand what experience people with learning disabilities have of services, a series of studies covering the following should be conducted:

- The experiences and life course trajectories of young people (aged 13–17 years) in terms of their aspirations and goals, including whether the support they and their families get affects their mental health and their expected outcomes as they prepare for adulthood.
- The experience people have of mental health inpatient services (specialist learning disability services or non-specialist services), including factors that may have prevented the need for admission and how inpatient admission affects them. Studies should include economic modelling.
- The experience people have of being discharged from mental health inpatient services (specialist learning disability services or non-specialist services), after a stay of one year or more. In particular: the factors that may have helped them to be discharged earlier, what support is effective after discharge, and how to lower the risk of readmission.
- The experiences people have during a crisis, including how effective crisis support is in meeting their needs, minimising risk and helping them recover.

- The experiences of people with milder learning disabilities (including people on the autistic spectrum) and common mental health problems (such as anxiety or depression) in accessing community-based interventions.

ISBN: 978-1-4731-2048-8

Accreditation