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

NICE guideline: short version

Draft for consultation, March 2016

This guideline covers the prevention, assessment and management of mental health problems in people with learning disabilities in all settings. This includes health, social care, educational, forensic and criminal justice settings.

Who is it for?

- Commissioners and providers of health and social care services.
- Schools and other education services.
- All health and social care professionals working with people with learning disabilities (with or without mental health problems) in community (including fostering, residential and kinship care), primary care, secondary care and secure settings.
- All educational staff working with:
  - children and young people with learning disabilities (with or without mental health problems) in schools and other educational settings (including early years)
  - adults with learning disabilities (with or without mental health problems) in educational settings.
- People of all ages with learning disabilities and mental health problems, and their family members and carers.

This version of the guideline contains the recommendations, context and recommendations for research. The Guideline Committee's discussion and the evidence reviews are in the full guideline.

Other information about how the guideline was developed is on the project page. This includes the scope, and details of the Committee and any declarations of interest.

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Contents

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 with mental health problems in relevant NICE guidance (see alcohol-use disorders, antisocial behaviour and conduct disorders, attention deficit hyperactivity disorder, autism, depression, eating disorders, obsessive-compulsive disorder, post-traumatic stress disorder, psychosis and schizophrenia, self-harm – long-term management, self-harm – short-term management and social anxiety disorder)
- 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 (see mental health and behavioural conditions on the NICE website), 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 sections 1.8 to 1.11).

1.2 Organisation and delivery of 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 care pathways in collaboration with people with learning disabilities and mental health problems and their family members, carers or care workers (as appropriate).

1.2.2 The designated leadership team should ensure that care pathways:

- provide a person-centred integrated programme of care
- are negotiable, workable and understandable for people with learning disabilities and mental health problems, their family members, carers or care workers, and staff
- are accessible and acceptable to people using the services
- are responsive to the needs and abilities of people using the services.

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 all services, including those not covered by the care pathway
  - 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, 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.

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 reportable

- 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].

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.

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

[1] This recommendation and recommendations 1.5.5, 1.6.18, 1.7.3 and 1.7.4 update and replace recommendation 1.3.3.2 in the NICE guideline on supporting people with dementia and their carers in health and social care.

- speak to the person directly rather than talking about or over them
- use clear, straightforward and unambiguous language
- assess whether communication aids or someone familiar with the person's communication methods are needed
- make adjustments to accommodate sensory 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, 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 involving a family member, carer or care worker (as appropriate).

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, or for their family members, carers or care workers to do so if the person does not have decision-making capacity.

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 their family members, carers or care workers 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 (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 (see mental health and behavioural conditions on the NICE website) **or**
- referral to a mental health professional who can provide interventions in line with NICE guidelines.

1.5 Identification and referral

1.5.1 If a person with learning disabilities shows any changes in behaviour (such as loss of skills or needing more prompting to use skills, social withdrawal, irritability, avoidance or agitation), staff should consider a mental health problem.

1.5.2 Staff should consider using identification questions, adjusted as needed, as recommended in the NICE guidelines (see mental

health and behavioural conditions on the NICE website) to identify common mental health problems in people with learning disabilities.

1.5.3 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.

1.5.4 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.

1.5.5 Refer people with learning disabilities who have suspected psychosis or suspected dementia to a psychiatrist with expertise in assessing and treating mental health problems in people with learning disabilities[2].

1.6 Assessment

Conducting a mental health assessment

1.6.1 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 person's family members, carers or care workers (as appropriate)

[2] This recommendation and recommendations 1.2.9, 1.6.18, 1.7.3 and 1.7.4 update and replace recommendation 1.3.3.2 in the NICE guideline on supporting people with dementia and their carers in health and social care.

- 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.

1.6.2 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.

1.6.3 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.

1.6.4 When conducting mental health assessments, be aware:

- that an underlying physical health condition may be causing the problem
- that a physical health condition or cognitive impairment may mask an underlying mental health problem
- that mental health problems can present differently in people with more severe learning disabilities.

1.6.5 When conducting mental health assessments, take into account:

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

1.6.6 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
- review psychiatric and medical history, past treatments and response
- review physical health problems and any current medication
- review the nature and degree of the learning disabilities, including behavioural phenotypes (for example, autism and Prader–Willi syndrome)
- 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 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 161.6.19).

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

1.6.8 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 1.6.23) 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.

1.6.9 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.

1.6.10 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

1.6.11 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

1.6.12 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.

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

1.6.14 When assessing an adult with learning disabilities, consider using tools such as the Mini Psychiatric Assessment Schedules for Adults with Developmental Disabilities (Mini PAS-ADD) to support a clinical assessment.

1.6.15 When assessing 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).

1.6.16 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 mild or moderate learning disabilities or the carer supplement for people with any degree of learning disabilities).

1.6.17 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[3].

1.6.18 Designated practitioners in specialist learning disabilities services should complete a baseline assessment of adaptive behaviour with all adults with Down's syndrome who are receiving care from the service[4].

Risk assessment

1.6.19 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
- potential triggers
- causal and maintaining factors
- whether safeguarding protocols should be implemented
- the likelihood and severity of any particular risk.

1.6.20 Repeat risk assessments regularly.

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

1.6.22 Risk management plans should:

[3] This recommendation updates and replaces recommendations 1.5.1.2 and 1.6.2.7 in the NICE guideline on supporting people with dementia and their carers in health and social care.
[4] This recommendation and recommendations 1.2.9, 1.5.5, 1.7.3 and 1.7.4 update and replace recommendation 1.3.3.2 in the NICE guideline on supporting people with dementia and their carers in health and social care.

- 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
- be reviewed regularly and adjusted if risk levels change.

The mental health care plan

1.6.23 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.

1.6.24 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
- risk and crisis plans, if needed
- steps to minimise future problems.

1.6.25 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.

1.7 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 a learning disability.

1.7.1 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.

1.7.2 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.

1.7.3 Include the following in annual health checks:

- a review of 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)[5].

1.7.4 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)

[5] This recommendation and recommendations 1.2.9, 1.5.5, 1.6.18 and 1.7.4 update and replace recommendation 1.3.3.2 in the NICE guideline on supporting people with dementia and their carers in health and social care.

- a need for more prompting in the past few months[6].

1.8 Psychological interventions

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

1.8.1 For psychological interventions for mental health problems in people with learning disabilities, refer to the NICE guidelines on specific mental health problems (see mental health and behavioural conditions on the NICE website) and take into account:

- the principles for delivering psychological interventions (see recommendations 1.8.2–1.8.4) and
- the specific interventions recommended in this guideline (see recommendations 1.8.5–1.8.9).

1.8.2 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.

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

- develop and agree the intervention goals

[6] This recommendation and recommendations 1.2.9, 1.5.5, 1.6.18 and 1.7.3 update and replace recommendation 1.3.3.2 in the NICE guideline on supporting people with dementia and their carers in health and social care.

- 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).

1.8.4 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

1.8.5 Consider cognitive behavioural therapy, adapted for people with learning disabilities (see the intervention adaptation methods in 1.8.2), to treat depression or subthreshold depressive symptoms in people with mild or moderate learning disabilities.

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

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

1.8.8 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.

1.8.9 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.

1.9 Pharmacological interventions

1.9.1 For pharmacological interventions for mental health problems in people with learning disabilities, refer to the NICE guidelines on specific mental health problems (see mental health and behavioural conditions on the NICE website) and take into account the principles for delivering pharmacological interventions (see recommendations 1.9.2–1.9.8).

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

1.9.3 Before starting medication for a mental health problem in a person with learning disabilities:

- consult with specialists prescribing medication for any other conditions the person has (for example, neurologists providing epilepsy care when prescribing antipsychotic medication that

may lower the seizure threshold), to avoid possible interactions and polypharmacy

- assess the risk of non-adherence to the medication regimen or any necessary monitoring tests (for example, blood tests), and the implications for treatment
- provide support to improve adherence (see the NICE guideline on medicines adherence)
- consider providing support from community learning disabilities nurses, if needed (for example, when carrying out blood tests)
- agree monitoring responsibilities between primary and secondary care.

1.9.4 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.

1.9.5 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.

1.9.6 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 treatment will be reviewed
- plans to reduce or discontinue the medication, if appropriate.

1.9.7 For people with learning disabilities who are taking antipsychotic drugs and not experiencing psychosis:

- reduce or discontinue long-term prescriptions of antipsychotic drugs
- 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.

1.9.8 When switching medication, pay particular attention to discontinuation effects that may occur during titration.

1.10 Social and physical environment interventions and adaptations to prevent mental health problems

1.10.1 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.

1.10.2 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 young 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).

1.11 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 those provided at day centres
- take part in leisure activities, such as hobbies, which are meaningful to the person.

Reasonable adjustments may be needed to do this, 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.

Terms used in this guideline

Carer

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

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 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.

Mild learning disabilities

People with mild learning disabilities typically have an IQ of between 50 and 69. They can often live independently and care for themselves, managing most everyday tasks and working in paid employment. They need support in some areas (for example, budgeting, planning, time management, and understanding abstract or complex information).

Moderate learning disabilities

People with moderate learning disabilities typically have an IQ of between 35 and 49. They will have some language skills and can communicate their needs and wishes. However, they will require significant support in their communication, literacy, numeracy, personal care, motor coordination and social and personal development, and will need support in their everyday life.

Profound learning disabilities

People with profound learning disabilities typically have an IQ of less than 20. They have the highest level of care needs and also often have visual, hearing or movement impairments, autism, epilepsy or other health problems. Most need support with mobility. Many have complex health needs that need extensive support. They are likely to have considerable communication needs, may be unable to communicate verbally and usually have very limited understanding.

Severe learning disabilities

People with severe learning disabilities typically have an IQ of between 20 and 34. They might be able to communicate some of their needs with basic words, simple sentences and gestures. They need support with daily activities such as dressing, washing, eating and mobility, though they might be able to perform some of their personal care needs. Some people will have additional medical needs, such as epilepsy or sensory impairments.

Serious mental illness

This is defined in this guideline as severe and incapacitating depression, psychosis, schizophrenia, bipolar disorder, schizoaffective disorder and anxiety 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 educational staff.

Young people

Aged 13–17 years.

You can also see this guideline in the NICE pathway on [pathway title].

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

Context

People of all ages with all levels of learning disabilities can be affected by mental health problems. The mental health problems can, however, be difficult to identify when the person is not able to describe or express their distress, and when they have coexisting physical health problems. Mental health problems are often unrecognised, causing unnecessary distress. Psychosis, bipolar disorder, dementia, autism, attention deficit hyperactivity disorder and behaviour that challenges 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 mild, moderate, severe or profound 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.

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 Case identification tools for common mental health problems

Develop 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 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.

The tools should be readily available and useable in routine health and social care settings (such as by GPs or caregiving staff).

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

- sensitivity and specificity
- predictive validity.

2 Cognitive behavioural therapy for anxiety disorders in people with mild to moderate learning disabilities

For people with mild to moderate learning disabilities, what is the clinical and cost effectiveness of cognitive behavioural therapy (modified for people with learning disabilities) for treating anxiety disorders ?

Why this is important

While there is some evidence to suggest that cognitive behavioural therapy (CBT) may be useful in treating depression in people with learning disabilities, further research is 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 relatively 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.

Modifications of CBT need to be tested in large randomised controlled trials, and any modifications should be clearly explained and documented. Primary outcome measures could include:

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

3 Pharmacological interventions for anxiety disorders in people with autism and learning disabilities

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

Why this is important

Anxiety disorders are common in people with learning disabilities, and in particular in people with autism. However, there is no evidence on pharmacological interventions for anxiety disorders in people with learning disabilities. People with learning disabilities 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. It is likely that the uncertainty about side effects and effectiveness contributes to the lack of treatment or the under-treatment of mental health problems in people with learning disabilities. 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 with autism and learning disabilities.

Randomised controlled trials should be carried out to compare the clinical and cost effectiveness of pharmacological interventions for anxiety disorders in this population. Primary outcome measures could include:

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

4 Psychosocial interventions for people with severe to profound learning disabilities

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

Why this is important

People with severe to profound 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.

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 severe and profound learning disabilities. Primary outcome measures 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 severe and profound learning disabilities.

5 Treatment settings for psychosis in people with mild learning disabilities

For people with mild learning disabilities, what is the clinical and cost effectiveness of delivering treatment for psychosis within a learning disabilities service, compared with a generic mental health service (including with support from learning disabilities specialists)?

Why this is important

While service provision varies across the country, mental health and learning disabilities services have often worked separately. People with mild learning disabilities are often treated within a generic mental health service, but those services may not be equipped to address the needs of people with learning disabilities. It is not clear whether psychosis in people with mild to moderate learning disabilities is best treated by a generic mental health service (with support from learning disabilities specialists), or by a specific learning disabilities service.

Randomised controlled trials should be carried out to compare a learning disabilities service with a generic mental health service (with support from learning disabilities specialists) for the treatment of psychosis in people with mild to moderate learning disabilities. Primary outcome measures could include:

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

The service user and staff experience will also need particular attention, as will the organisational changes needed to deliver and maintain impacts.

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