

Why you should read this article:

- To recognise the challenges that may be involved in undertaking mental health assessments of people with learning disabilities
- To identify appropriate communication skills, strategies and approaches that can be used when conducting mental health assessments of people with learning disabilities
- To contribute towards revalidation as part of your 35 hours of CPD (UK readers)
- To contribute towards your professional development and local registration renewal requirements (non-UK readers)

Conducting mental health assessments of people with learning disabilities

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Abstract

Mental health issues are not only more prevalent in people with learning disabilities compared with the general population, but they are also more challenging to assess and diagnose. Reasons for this may include the communication issues and cognitive impairments often experienced by people with learning disabilities. This article describes some of the challenges that nurses and other healthcare professionals may encounter when assessing mental health issues in people with learning disabilities. It provides practical advice on how to conduct an effective mental health assessment and outlines a range of communication strategies that can be used to overcome any issues that occur.

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Keywords

accessible information, communication, diagnostic overshadowing, language, learning disability, mental health, patient assessment, patients, professional

Aims and intended learning outcomes

The aim of this article is to identify some of the challenges involved in conducting mental health assessments of people with learning disabilities and to provide practical advice for nurses on how to overcome these issues. After reading this article and completing the time out activities you should be able to:

- » Recognise the challenges that healthcare professionals may experience when assessing and diagnosing mental health issues in people with learning disabilities.

- » Identify appropriate communication skills, strategies and approaches to conducting mental health assessments of people with learning disabilities.
- » Consider how to enhance the experiences of people with learning disabilities, their families and carers during mental health assessments.
- » Explain to other members of the multidisciplinary team their responsibilities in relation to completing a mental health assessment of people with learning disabilities.

Introduction

Mental health issues are more likely to occur in people with learning disabilities compared with the general population (Office for Health Improvement and Disparities 2023). Prevalence figures vary depending on the criteria and the population they are taken from; however, contemporary studies have identified that 21% of people with learning disabilities had experienced mental health issues (Sheehan et al 2015), compared with 17% of the general population (Mental Health Foundation 2016).

Undertaking an assessment to identify mental health issues in people with learning disabilities can be challenging. Mental health issues are often overlooked in people with learning disabilities because some healthcare professionals may believe that these individuals cannot participate in an assessment because of a perceived lack of communication skills (Chaidemenaki 2021). This issue can occur due to the healthcare professional's inexperience of working with people with learning disabilities, for example not recognising the atypical presentation of signs and symptoms that can occur in this population (Deb et al 2022). Additionally, some symptoms may be missed because of diagnostic overshadowing, where psychopathology is wrongly attributed to the individual's learning disability rather than mental health issues (Standen et al 2017).

Diagnostic overshadowing can be further affected by the additional physical health issues that people with learning disabilities often experience (Hatton et al 2014). For example, hypothyroidism in people with Down's syndrome can have a similar presentation to depression or dementia (National Institute for Health and Care Excellence (NICE) 2016, Zalzal and Lawlor 2023), while higher rates of chest and urinary infections can cause sudden onset of confusion which can be mistaken for part of the individual's presentation (Hosking et al

2017). In addition, people with learning disabilities may experience increased side effects from medicines such as beta blockers and benzodiazepines, which can trigger symptoms of mental health issues (Winterhalder and Paton 2011). For some individuals, these issues may remain undetected and untreated, making the diagnostic picture unclear (Public Health England 2015). Any underlying physical health conditions need to be ruled out before attributing the symptoms to mental health issues (Hughes-McCormack et al 2017). This means that mental health issues in people with learning disabilities can be unrecognised, under-investigated and untreated (Standen et al 2017).

Another issue is that people with learning disabilities may also find it challenging to recognise and interpret their symptoms (Abreu et al 2018). This can lead to a greater use of vicarious assessments through third parties, including family members, carers and paid staff members. Staff often lack training in, and knowledge of, mental health in people with learning disabilities (Adams 2019).

Communication is required for an individual to report their symptoms subjectively, so diagnosing mental health issues is challenging in people with limited capacity to communicate (Public Health England 2015), as they may not be able to explain their experiences (Hemmings and Bouras 2010). Therefore, it may be easier to identify observable behavioural changes associated with a mental health issue instead. For example, loss of appetite, changes in sleep patterns or weight loss can be identified and measured objectively to indicate a mental health issue such as depression (Sikabofori and Iyer 2012a). Learning disability nurses have an essential role in assessing mental health issues in people with learning disabilities, planning and coordinating care that meets their needs, and working collaboratively with the multidisciplinary team to provide support.

Key points

- Assessing people with learning disabilities and mental health issues is a complex process and effective communication strategies are essential
- The challenges associated with assessing people with learning disabilities and mental health issues are often due to the communication issues and cognitive impairments that they may experience
- When undertaking mental health assessments of people with learning disabilities, ensure the environment is suitable, use appropriate language, include family and carers, and adopt a person-centred approach
- Learning disability nurses should develop their communication skills and make adaptations when assessing people with learning disabilities and mental health issues

TIME OUT 1

Think of a person with learning disabilities you have worked with who was diagnosed with a mental health issue. Did they have additional physical health conditions or behaviour that challenges which made identifying the signs and symptoms of their mental health issue more challenging? If so, what enabled colleagues to identify the mental health issue accurately?

Communication and mental health issues in people with learning disabilities

People with learning disabilities may have challenges in making sense of their environment, as well as in giving and receiving information (Boardman et al 2014, Foundation for People with Learning Disabilities 2023). In some cases an individual may have expressive communication skills that exceed their receptive decoding of information; that is, they may use certain words when talking, but not have a full understanding of what these words mean when used by someone else. At other times, an individual may use a word or term incorrectly. For example, during a mental health assessment a person may describe having ‘bats in their stomach’ when attempting to convey that they have ‘butterflies in their stomach’; this could be misinterpreted by the healthcare professional as a delusional belief rather than the misuse of a common phrase. In addition, people with learning disabilities may find it challenging to express how they feel and/or have further visual, hearing and cognitive impairments (NHS Education for Scotland 2015).

People with learning disabilities need to be able to understand if their symptoms relate to a mental health issue and convey this to others. The healthcare professional conducting the assessment needs to confirm that the symptoms that are being described relate to a mental health issue and are not occurring for other reasons. For example, a person with anxiety and depression may identify issues with sleeping as being due to coughing or snoring (Bond et al 2020). Sometimes, the physical signs of mental health issues may be easier for an individual

to communicate rather than emotional and subjective symptoms. For example, a person with anxiety may report physical signs such as sweating, increased heart rate or hyperventilation, rather than describing emotional symptoms such as fear or feelings of dread (Sikabofori and Iyer 2012b).

TIME OUT 2

Discuss with a colleague whether they have ever had to adapt the way they communicate when conducting a mental health assessment with someone with learning disabilities. What areas did they need to focus on? Were there any assumptions they needed to avoid making?

Communication skills, strategies and approaches**Language use and power dynamics**

During an assessment, an individual with a learning disability may frequently use colloquial terms – such as ‘belly’, ‘nutter’ or ‘bonkers’ – rather than medical terminology (Boardman et al 2014). This may result in the healthcare professional having to change the type of language that they use. If the individual being assessed has a preferred term, the healthcare professional may need to adopt this term too (NICE 2016). It is important that the healthcare professional does not appear to be condescending or engaging in ‘childish talk’ (Rapley 2004) and they should take their lead from the individual.

The healthcare professional needs to be aware of their position of power when conducting an assessment, as they will often be in control of this process (Callus and Cauchi 2020). This can cause an inadvertent power dynamic, making the person with learning disabilities increasingly suggestible or increasing their likelihood of acquiescing, for example by answering questions in a way that they believe the healthcare professional wants them to answer (Newell and Burnard 2011, Northway and Hopes 2022). This makes ‘leading questions’ (those that prompt or encourage the desired answer) a particular issue, and healthcare professionals should

avoid influencing individuals' answers during an assessment (Moule 2018). Healthcare professionals should be aware that this power dynamic could be compounded by their demeanour, such as wearing a uniform, formal clothing or a name badge (Bradley and Lofchy 2005), which may make them appear more authoritarian.

People with learning disabilities may give answers that they think will result in them being viewed more positively, rather than answering truthfully if they think the outcome will be a negative view of them. This is described as using a 'cloak of competence' (Edgerton 1993), whereby a person with learning disabilities may want to appear to be less impaired, appear to not have a mental health issue or to avoid anything that they feel is stigmatising. The person may feel the assessment is something that they are required to 'pass' rather than it being about providing objective information (Kittelsaa 2014). They might also want not to appear 'stupid' and so pretend to understand what they are being asked rather than admit that they do not understand (Northway and Hopes 2022).

Box 1 provides advice on communicating with people with learning disabilities.

Environment and psychological safety

The environment where the assessment takes place is an important consideration. The British Psychological Society (2015) recommends using a well-lit, comfortable and distraction-free room. As well as physical comfort, psychological safety is important as emotional discomfort can affect the results of the assessment, for example an individual may appear more anxious if they find their surroundings distressing (Northway and Hopes 2022). Additionally, people with learning disabilities may find ambiguous situations anxiety provoking (Klein et al 2018), while even discussing anxiety can trigger anxiety, so all possible actions should be taken to make the assessment feel relaxed.

A healthcare professional should explain to the individual in advance why they are being asked questions and what will be done with the information they provide. People with learning disabilities may have concerns about confidentiality and be reluctant to discuss information they think might be relayed to their parents or staff (NICE 2016).

Box 1. Advice on communicating with people with learning disabilities

Do:

- » Establish if the person being assessed has a preferred communication strategy or any form of communication passport
- » Use active verbs and stay in the present tense. For example, ask 'Do you like going to the day centre?' rather than 'Is the day centre somewhere that you like going to?'
- » Use nouns rather than pronouns. For example, rather than saying 'Your appointment is with Jane, it starts at nine o'clock and it will last 30 minutes,' consider saying 'Your appointment is with Jane, your appointment starts at nine o'clock and your appointment will last 30 minutes'
- » Use simple terms rather than medical jargon, and ensure the terms used are understood by the person
- » Once a word has been used to describe something, continue to use that word from then on
- » Use 'anchor events' to assist the person to recall past events and information (Mindham and Espie 2003). For example, rather than asking 'How long have you been having these thoughts?' an anchor event can be inserted as an aide-mémoire, such as 'Have you felt this way since Christmas?' 'Have you felt like this since you came back from holiday?' or 'Were you feeling like this in your last job?'
- » An individual may automatically answer 'yes' or 'no' to every question, which is sometimes referred to as 'yea-saying' or 'nay-saying'. To confirm the answer given, subtly reverse the question
- » Be aware of the power dynamic. Consider an appropriate venue and whether wearing a uniform, formal clothing or name badge may be intimidating to the person
- » Use assessment tools specifically designed for people with learning disabilities (National Institute for Health and Care Excellence 2016). These can assist in framing the questions as they will have accompanying images
- » Consider guidance on communicating with people with learning disabilities from Mencap (2018), the government's accessible information standard (NHS England 2017) and the Royal College of Speech and Language Therapists (2013), as well as advice on communicating with people with learning disabilities who may have mental health issues (Hardy et al 2011)

Do not:

- » Use abstract concepts, for example asking a person if they are 'feeling low,' since this may be challenging for the person to understand. Instead, consider asking 'Are you crying more than usual?' as this question is easier to answer because the person can identify this concrete sensation
- » Use lengthy sentences or ask multiple questions at once. Instead, keep sentences short and concise and ask one question at a time
- » Use double negatives, for example 'Do not call me on weekends, when I will not be at work.' Instead say 'Call me Monday to Friday'
- » Use leading questions, which may encourage the individual to reply 'yes' or 'no'. For example 'Your mum has said that you've been feeling low, is this right?' suggests an answer of 'yes,' while 'You haven't been drinking alcohol, have you?' suggests an answer of 'no'
- » Offer lengthy options, because the person may choose the last item on a long list because it is freshest in their mind. Instead, offer two choices at a time, let the person select one of these, then offer a new option along with their last preferred choice. This means they are only ever choosing from two options

Anxiety can also be provoked by the way questions are phrased; open questions are usually recommended because they make the individual expand on their answers, so they cannot easily acquiesce with the healthcare professional. However, some people may find open questions anxiety provoking (Boardman et al 2014). Closed questions and even 'yes or no' questions may be required if the individual appears to find it challenging to answer broader enquiries.

At the start of the assessment, the individual's personal state needs to be considered. Ill health, side effects of medicines, fatigue, hunger or disrupted sleep may affect the assessment of someone with learning disabilities (Morrison et al 2021).

Individual communication abilities

When conducting assessments with people with learning disabilities, the healthcare professional may notice a significant delay between asking the question and the individual formulating their answer. They may feel tempted to repeat the question, based on an assumption that it was not understood or that it needs to be rephrased. However, continuous prompting could disrupt the individual's thought process, so it is important to give them sufficient time to express themselves (Boardman et al 2014). If they ask for a question to be reframed it is acceptable to do so.

An individual may have challenges recalling events in time (Sikabofori and Iyer 2012a), for example how long they have had a particular symptom. In addition, they may have issues with recall such as the recency effect, whereby an individual is given several answers to choose from and they may select the last one on the list because it is the freshest in their mind. The healthcare professional should also be aware that the individual may use echolalia, whereby they repeat words or phrases they have just heard, or they might appear to engage in conversation but their responses are prompted by the context rather than them giving an accurate response to a question (Northway and Hopes 2022).

Numerical rating scales are sometimes used in an assessment; for example, the healthcare professional might ask, 'Tell me on a scale of one to ten, how bad it is?' However, it can be challenging for people with learning disabilities to express their feelings quantitatively in this way. Sometimes images are used to assist with this, such as 'smiley face' or 'sad face' images. If these are being used as an adjunct to communication, the healthcare professional needs to consider that the person may just point to the 'smiley face' as it is the most appealing image (Rapley 2004).

If the individual being assessed has delusional beliefs, these may appear to be less grandiose than in those without learning disabilities. For example, someone with learning disabilities may believe that they have a new job, can drive a car or are in a sexual relationship when this is not the case. These can be missed because they are not particularly unusual but they could be grandiose delusional beliefs for someone who has a limited lifestyle. Third-party verification from the person's family members, carers or friends may be necessary. Delusional beliefs need to be within the individual's realm of understanding; for example, complicated delusions involving the internet, satellites and technology will not be prominent if the individual does not understand these (Hemmings and Bouras 2010).

Conversely, a person's real-life experiences may be mistaken for delusions. An example is an individual who states that others are 'out to get them', insulting them or threatening them, which a healthcare professional might perceive as persecution or paranoid ideas. However, these could be accurate descriptions of the experiences of people with learning disabilities who are living independently in the community, where they may be the victim of hate crimes.

Person-centred approach

When undertaking an assessment, it is essential to ensure that communication is person-centred. Knowing the individual

well or engaging with someone who does can assist with this. The healthcare professional may need to enquire if the individual has any sensory impairments and requires glasses or hearing aids, rather than assuming the person will volunteer this information. Sometimes general advice for improving communication may be contraindicated. For example, it is widely accepted that eye contact enhances communication, but this may not be appropriate when assessing someone who is autistic (Sturrock et al 2022).

Generally accepted skill levels, such as being able to read, write or having numeracy skills, may not be apparent in someone with learning disabilities. For example, the 'serial sevens' task, where someone is asked to count backwards from 100 in steps of seven, is part of the Mini Mental State Examination (MMSE) (Molloy et al 1991), but it may be too challenging a task for a person with a learning disability. Similarly, other MMSE questions, such as spelling the word 'WORLD' backwards, may be outside the individual's baseline level of understanding. When undertaking an assessment, the healthcare professional would need to adapt these standardised assessment methods to meet the individual's abilities. Having baseline information about the person's skill levels to compare with can assist in the assessment process.

Family and carer involvement

There may be times where vicarious assessment is required; that is, a family member or carer may need to be involved in the assessment, with the person with learning disabilities remaining at the centre of care (NICE 2015). This could be because the individual has severe learning disabilities or pronounced communication issues. Family members and carers are likely to be aware of any changes in behaviour, loss of skills, functioning or other signs of distress that might indicate mental health issues (NICE 2016).

Involving carers in this way can also cause issues that may hinder the assessment process. High staff turnover means that any

new carer or staff member who is involved in the assessment may have known the individual for only a short time and have incomplete knowledge of them (NICE 2016), meaning that they might not be able to identify behavioural changes over time. In addition, the high use of agency staff can mean that a carer or staff member has only worked with the person on a few occasions. It is important to ascertain the level of knowledge a carer or staff member has about the person when obtaining any information from them. Other issues can occur if staff do not want to appear to be failing so present a more positive picture.

Confirmation bias is another factor that needs to be considered when staff are involved in an assessment. It can occur when a healthcare professional has decided on a diagnosis and then seeks evidence to support it. For example, a healthcare professional may decide that a person has dementia and then note any behaviour that appears to confirm this, while ignoring other behaviours.

It is important to check with the person with learning disabilities that they are happy for a family member or carer to be present at their assessment because having another person there could cause the individual to answer questions more hesitantly. It is also important not to speak over the person with learning disabilities or to focus on their family member or carer.

The use of assessment tools with the person directly and/or with their family members and carers can also be beneficial. NICE (2016) guidelines recommend the use of mental health assessment tools that have been developed or adapted for people with learning disabilities, some of which are listed in Box 2.

TIME OUT 3

How is the NICE (2016) guideline on the prevention, assessment and management of mental health issues in people with learning disabilities applied in your area of practice? What barriers are there to its application? How could these be overcome?

FURTHER RESOURCES

Easy Health
easyhealth.org.uk
 Foundation for People
 with Learning Disabilities –
 Easy Read
www.learningdisabilities.org.uk/learning-disabilities/a-to-z/e/easy-read
 NHS England – Easy read
 information
england.nhs.uk/learning-disabilities/about/resources/er

Strategies to support effective communication

Some people with learning disabilities may experience challenges with using expressive and receptive language, so the following strategies can be used to support them:

- » Makaton (makaton.org).
- » Picture Exchange Communication System (PECS) (pecs-unitedkingdom.com/pecs).
- » Easy read symbols.
- » Speech and language therapy involvement.
- » Communication passports.
- » Books Beyond Words (booksbeyondwords.co.uk).
- » Communication boards.
- » Talking Mats (talkingmats.com).
- » Social stories, objects and images.

TIME OUT 4

Based on your experience of assessing people with learning disabilities, list the essential skills required to undertake an effective mental health assessment. Which of these skills could you develop further? What additional support might you need to achieve this?

Role of learning disability nurses

Learning disability nurses can screen the referrals they receive and gather information on how an individual being assessed communicates. They can complete the nursing assessment and risk assessment using a biopsychosocial approach (Sheerin et al 2019). Additionally, they can establish the person's history from the individual and people who know them well, and make referrals for specialist assessment (for example, to a clinical psychologist or

psychiatrist), and ensure shared decision-making. Learning disability nurses can support access to mental health services and educate other healthcare professionals on the needs of people with learning disabilities, ensuring that reasonable adjustments are implemented where necessary (Mafuba et al 2020). While assessing for mental health issues, learning disability nurses should consider the person's risk to self and others, self-neglect, vulnerability to exploitation, potential triggers, causal and maintaining factors, and if safeguarding arrangements need to be implemented (NICE 2016, Mafuba et al 2020).

Learning disability nurses may be able to identify subtle changes in a person's behaviour over time and liaise with significant others in the person's life about this. This may be particularly pertinent when assessing people with severe learning disabilities or pronounced communication issues, in whom there may be a greater reliance on looking for subtle behavioural changes that could indicate a mental health issue.

TIME OUT 5

Reflect on your experiences of working in a multidisciplinary team. What information have you been able to provide to others to assist them in undertaking assessments of people with learning disabilities? What have you learned about assessment from other professionals?

Conclusion

The assessment and diagnosis of mental health issues in people with learning disabilities is often challenging and complex, in part due to the communication issues and cognitive impairments that this population often experiences. When assessing people with learning disabilities, healthcare professionals need to adopt effective communication strategies and use tools that have been specifically developed or adapted for this population. Learning disability nurses are well placed to ensure that mental health assessments of people with learning disabilities are undertaken effectively.

Box 2. Commonly used mental health assessment tools for people with learning disabilities

- » The Glasgow Depression Scale for people with a Learning Disability (GDS-LD) (Cuthill et al 2003)
- » The Glasgow Anxiety Scale for people with an Intellectual Disability (GAS-ID) (Mindham and Espie 2003)
- » The Psychiatric Assessment Schedules for Adults with Developmental Disabilities (PAS-ADD) (Moss 2012) and the Moss-PAS for adults with Intellectual Disabilities (Moss-PAS (ID)) family of instruments (Moss 2019)
- » Dementia Screening Questionnaire for Individuals with Intellectual Disabilities (DSQIID) (Deb et al 2007)

TIME OUT 6

Identify how conducting mental health assessments of people with learning disabilities applies to your practice and the requirements of your regulatory body

TIME OUT 7

Now that you have completed the article, reflect on your practice in this area and consider writing a reflective account: rcni.com/reflective-account

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Test your knowledge by completing this multiple-choice quiz

Mental health assessments

1. Why might it be challenging to identify mental health issues in people with learning disabilities?

- a) Communication issues ☐
- b) Cognitive impairments ☐
- c) Diagnostic overshadowing ☐
- d) All of the above ☐

2. A person whose expressive communication skills exceed their receptive decoding of information:

- a) May use certain words when talking, but not fully understand what they mean when used by someone else ☐
- b) Will easily understand information communicated to them ☐
- c) Will frequently misspell words ☐
- d) Will be unable to communicate verbally ☐

3. One strategy that healthcare professionals can use during an assessment is to:

- a) Use leading questions to get the answer they want ☐
- b) Wear formal clothing and a name badge to make themselves appear authoritarian ☐
- c) Adopt an individual's preferred terms and language ☐
- d) Influence individuals' answers as much as possible ☐

4. Which statement is false?

- a) People with learning disabilities can find ambiguous situations anxiety provoking ☐
- b) Anxiety can be provoked by the phrasing of questions ☐
- c) Healthcare professionals should avoid explaining to the individual in advance why they are being asked questions as this will increase their anxiety ☐
- d) Emotional discomfort can affect the results of a mental health assessment ☐

5. When communicating with people with learning disabilities:

- a) Ask multiple questions at once ☐
- b) Use active verbs and stay in the present tense ☐
- c) Offer lengthy options ☐
- d) Use abstract concepts ☐

6. Using 'anchor events' can:

- a) Assist the person to recall past events and information ☐
- b) Encourage the person to answer 'yes' or 'no' to all questions ☐
- c) Exacerbate the power imbalance between the person and the healthcare professional ☐
- d) Prevent the person from identifying concrete sensations ☐

7. What term is used to describe an individual repeating words or phrases they have heard?

- a) Echolalia ☐
- b) Recency effect ☐
- c) Confirmation bias ☐
- d) Cloak of competence ☐

8. Which statement is false?

- a) A staff member or carer may need to be involved in the assessment if an individual has severe learning disabilities or pronounced communication issues ☐
- b) It is important to check the person is happy for a staff member or carer to be present at their assessment ☐
- c) Family and carers may be aware of any changes in behaviour, loss of skills, functioning or other signs of distress that may indicate mental health issues ☐
- d) It is acceptable to speak over a person with learning disabilities and focus on their family member or carer ☐

9. Which strategy should not be used to support people who find expressive and receptive language challenging?

- a) Makaton ☐
- b) Medical jargon ☐
- c) Easy read symbols ☐
- d) Communication passports ☐

10. The role of learning disability nurses may involve:

- a) Gathering information on how an individual communicates ☐
- b) Educating other healthcare professionals on the needs of people with learning disabilities ☐
- c) Ensuring that reasonable adjustments are implemented ☐
- d) All of the above ☐

How to complete this assessment

This multiple-choice quiz will help you test your knowledge. It comprises ten multiple choice questions broadly linked to the previous article. There is one correct answer to each question.

You can read the article before answering the questions or attempt the questions first, then read the article and see if you would answer them differently.

You may want to write a reflective account. Find out how at rcni.com/reflective-account

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This multiple-choice quiz was compiled by Alex Bainbridge

The answers to this quiz are:

1. d 2. a 3. c 4. c 5. b 6. a 7. a 8. d 9. b 10. d



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