Evidence & practice / CPD / assessment of psychiatric disorders

Why you should read this article

- People with learning disabilities are more likely to have mental ill-health, yet it can be more difficult to assess.
- There are several reasons assessment is difficult with additional challenges conducting interviews and adapting communication. There are appropriate enhanced communication skills, strategies and approaches that can be used to ensure effective assessment, which this article discusses.
- Other members of the multi-disciplinary team (MDT) might have limited understanding of your role. Reading this article will support you to explain to other MDT members your responsibilities in relation to completing an assessment in people with learning disabilities and mental ill-health.

Effective communication and assessment skills with people with learning disabilities and mental ill-health

Abstract

Mental ill-health is more prevalent in people with learning disabilities, yet more difficult to assess and diagnose. This is due to several reasons and the main one being communication difficulties experienced by people with learning disabilities. Learning disabilities nurses have a role in assessing people with learning disabilities and mental ill-health. This article describes some of the challenges encountered in assessing mental health problems in people with learning disabilities. It explores the interview process and complications from interaction with third parties such as staff or family and/or carers. This article provides practical advice as to how to conduct an effective assessment.

Author details:

Keywords

Communication, assessment, mental health

Aims and intended learning outcomes

This article aims to highlight some of the difficulties with assessment interviews in people with learning disabilities and provide practical advice to overcome these problems. Readers are encouraged to review their experience of assessing people with learning disabilities and mental ill-health.

After reading this article and completing associated Time Out Activities the reader will be able to:

1. Identify appropriate communication skills, strategies and approaches.
2. Enhance the experiences of people with learning disabilities, their family and carers during assessment.
3. Explain to other members of the multidisciplinary team their responsibilities in relation to completing a mental health assessment in people with learning disabilities.

Introduction

Mental ill-health is more likely to occur in people with learning disabilities than in the general population (Office for Health Improvement and Disparities 2022). Prevalence figures vary depending on criteria and the population they are taken from, contemporary studies identify prevalence at 21% (Sheehan et al 2015), slightly elevated compared to 17% seen in the wider population (Hughes-McCormack et al 2017).

Identifying mental ill-health in people with learning disabilities can be more challenging than the usual assessment process. The relationship between learning disabilities and mental ill-health is often overlooked as it is sometimes believed that people with learning disabilities cannot participate in the assessment due to perceived lack of communication skills (Chaidemenaki 2021). This can be due to the assessor's inexperience of working with people with learning disabilities, for instance, not recognising the atypical presentation of signs and symptoms that can occur in people with learning disabilities (Matson et al 2007). Other symptoms can be missed due to diagnostic overshadowing, where psychopathology is wrongly attributed to the individual's learning disabilities rather than mental ill-health (Standen et al 2017). Diagnostic overshadowing can be further impacted by the additional physical health problems people with learning disabilities have (Hatton et al 2014). For example, hypothyroidism (Prasher 1999) can have similar presentation to depression or dementia (NICE 2016); higher rates of infections can cause delirium (Hosking et al 2017); accompanied by increased medication side effects (Winterhalder and Paton, 2005). For some individuals, these might

remain undetected and untreated clouding the diagnostic picture (Glover et al 2015). Any underlying physical health conditions must be ruled out prior to attributing the symptoms to mental ill-health (Hughes-McCormack et al 2017). This means mental ill-health in people with learning disabilities can be unrecognised, under-investigated, and untreated (Standen et al 2017).

As well as the problems professionals might have identifying signs of mental ill-health, people with learning disabilities may also have difficulty recognising and interpreting their own symptoms (Abreu et al 2018). This can lead to a greater use of vicarious assessments through third parties, including paid staff, family, and other informal carers. Staff often lack training and knowledge regarding mental health (Adams 2019).

Mental ill-health that has observable behavioural changes might be easier to identify. For instance, a loss of appetite, changes in sleep pattern or weight loss can be identified and objectively measured indicating mental disorder (Sikabofori and Iyer 2012a). However, communication is required to get an individual's subjective report of symptoms. Establishing psychiatric illness is difficult in people with limited capacity to communicate (Glover et al 2015) as without the individual explaining their experiences mental ill-health cannot be accurately diagnosed (Hemmings and Bouras 2010). Learning disabilities nurses have a pivotal role in assessing people with learning disabilities with mental ill-health, to plan and coordinate their care, and work collaboratively with the MDT to support them to meet their needs.

Time Out Activity 1:

Think of an individual you have worked with diagnosed with a mental health problem. Did they have additional physical ill-health or behavioural challenges that made identifying the signs and symptoms of their mental health problem more difficult?

If so, what enabled colleagues to correctly identify the mental health problem?

Communication and mental ill-health in people with learning disabilities.

People with learning disabilities may have difficulty making sense of their environment compared to the general population (Foundation for People with Learning Disabilities 2022). People with learning disabilities can have problems with both giving and receiving of information (Broadman et al 2014). In some cases, an individual may have expressive communication skills which exceed their receptive decoding of information. They may use words when talking, but not have a full understanding of what these words mean when used by someone else. At other times, an individual could use a word or term

incorrectly. For instance, a man, during assessment, describes having 'bats in his stomach' when he is trying to convey that he has 'butterflies in his stomach', this could be misinterpreted by the assessor as a delusional belief rather than the misuse of a common phrase. In addition, they have difficulties expressing how they feel as well as having further visual, hearing, and cognitive impairments (NHS Education for Scotland 2015).

People with learning disabilities need to be able to understand that their symptoms relate to a mental illness and convey this. An assessor needs to confirm that the symptoms that are being described relate to a mental health problem and are not occurring for other reasons. For example, someone with anxiety and depression may identify problems with sleeping as being due to coughing or snoring (Bond et al 2020). Sometimes, the physical signs of a mental ill-health may be easier for an individual to communicate rather than emotional and subjective symptoms. For instance, someone who is anxious may report the physical, somatic signs of anxiety such as sweating, increased heart rate or hyperventilation, rather than describing symptoms such as fear or feelings of dread (Sikabofori and Iyer 2012b).

Time Out Activity 2:

Discuss with a colleague whether they have ever had to adapt the way they communicated when conducting an assessment interview with someone with learning disabilities.

What did they need to concentrate upon more?

Were there any assumptions they found that they needed to resist?

Communications skills, strategies and approaches that the practitioner needs

Language use

Depending on the individual being assessed, there may be a greater reliance on colloquial terms rather than medical terminology (Broadman et al 2014), such as, '*belly*', '*nutter*', '*poo*', '*bonkers*'. This may result in the assessor having to change the type of language that they use themselves. If the individual being assessed has a preferred term, the assessor may have to adopt this term too (NICE 2016). It is important, that the assessor does not appear condescending or engaging in 'childish-talk' (Rapley 2004) and should take their lead from the interviewee.

The assessor needs to be aware of the position of power they are in when interviewing, where often they are in control (Callus and Cauchi 2020). This can cause an inadvertent power dynamic, making the individual with learning disabilities more suggestible or increase the likelihood of acquiescing (Northway and Hope 2022). This could result in answering in a way they believe the assessor wants them to (Newell and Burnard 2011). This makes 'leading questions' even more of an issue and assessors should avoid shaping respondents' answers (Moule 2018). This power dynamic could be compounded by the assessor's demeanour, such as wearing uniform, formal clothing or name tags (Bradley and Lofchy 2005), which may make them appear more authoritarian. Further to this, interviewees may give answers that they feel will make them be viewed more positively rather than answering truthfully, if they feel this will give a negative view of them. This is described as using a 'cloak of competence' (Edgerton 1993) and someone with learning disabilities may want to appear to be less disabled, not appear to have a mental health problem or avoid anything that they feel is stigmatising. An individual may feel the assessment is something that they are required to 'pass' rather than about providing objective information (Kittelsaa 2014). The person being assessed may not want to appear stupid, they may pretend to understand what they are being asked rather than admit that they do not comprehend (Northway and Hopes 2022).

Please see the examples in the two breakout boxes on 'overcoming communication problems' giving dos and don'ts whilst assessing towards the end of this article.

Environment

Another consideration is the environment that the assessment takes place in. The British Psychological Society (2015) recommend a well-lit, distraction-free room, that is physically comfortable. As well as physical comfort, psychological security is important and emotional discomfort can skew the results of the assessment, with the individual appearing more anxious if they are distressed with their surroundings (Northway and Hopes 2022). People with learning disabilities can find ambiguous situations anxiety provoking (Klein et al 2018). Even discussing anxiety can trigger anxiety, so everything possible should be done to make the assessment relaxed. It should be explained to the individual in advance why they are being asked questions and what will happen with that information. People with learning disabilities can have concerns regarding confidentiality and be reluctant to discuss information that they think might be relayed to their parents or staff (NICE 2016). Anxiety can also be provoked by the way that questions are phrased, open questions are usually recommended as they make the individual expand on their answers so they cannot acquiesce so easily. However, some may find open questions anxiety provoking (Broadman et al 2014). Closed questions and even 'yes/no' questions may be required if the individual appears to have difficulty answering more broader

enquiries. At the start of the assessment, the individual's personal state needs to be considered, ill-health, medication side-effects, fatigue, hunger, or disrupted sleep may have a larger impact on someone with learning disabilities and effect the interview (Morrison et al 2021).

Individual communication abilities

When asking questions, an assessor may notice a significant delay in asking the question and the individual formulating their answer. The temptation might be to repeat the question again, with the assumption it was not understood or that it needs to be phrased differently. However, continuous prompting, could disrupt the interviewee from their thought process. It is important to give the individual enough time to express themselves (Hagiliassis et al 2006). If they ask for a question to be reframed, it is acceptable to do so.

An individual may have difficulty recalling events in time (Sikabofori and Iyer, 2012a), for example, how long they have had a particular symptom. In addition, there may be problems with recall such as the recency effect, where an individual is given several answers to choose from, they may select the last one on the list as it is the most recent. The assessor should be aware of echolalia, where words or phrases may be repeated by the individual, appearing to engage in conversation when their 'replies' may be triggered by context rather than giving an accurate response to a question (Northway and Hopes 2022).

Rating scales are sometimes used in assessment, such as "tell me on a scale of one to ten, how bad it is?". It can be difficult to express feelings quantitatively in this way. Sometimes images are used to assist with this such as a 'smiley-face' or 'sad-face' images. If these are being used as an adjunct to communication, it needs to be considered that the person may just point to the most appealing image, like the 'happy looking' face (Rapley 2004).

If someone with delusions is being interviewed, these may be less grandiose. For example, someone with learning disabilities may state that they have a new job, can drive a car or are in a sexual relationship. These can be missed because they are not particularly unusual but could be grandiose delusional beliefs to someone who has a limited lifestyle. Third party verification may be needed. Delusions must be within the individual's realm of understanding, and as a result may not be very complex. Complicated delusions involving the internet, satellites and technology will not be prominent if the individual does not understand these (Hemmings and Bouras 2010). Conversely, there may be an over estimation of delusions, when the person being assessed describes what can appear to be persecutory or paranoid ideas. This could be stating that others are 'out to get them', insulting them

or threatening them, these could all be accurate descriptions of the lives some people with learning disabilities living independently in the community, where they may be the victim of hate crime.

Person-centred approach

The most important aspect of communication during assessment is to make sure that it is person-centred. This is helped by knowing the individual well or engaging with someone who does. Enquiring if the individual has any sensory impairments or may require glasses or hearing aids may need to be instigated by the interviewer rather than assuming the individual will volunteer this information. Sometimes general advice for improving communication may be counter-indicated. For example, it is widely accepted that good eye-contact enhances communication, however, this may be less appropriate interviewing someone who has autism (Sturrock et al 2021). Having baseline data can assist in the interview process. Usual accepted skill levels, such as being able to read, write or having numeracy skills may not be apparent in someone with learning disabilities. This can make assessment more challenging with no baseline to compare with. For example, the 'serial sevens' task, where someone is asked to count downwards from 100 in steps of seven, is a long-standing part of the mini mental state examination but this may be too difficult a task (NICE 2016). Similarly, other mini mental state examination questions, such as spelling the word 'WORLD' backwards may be outside the individual's baseline level of understanding. An assessor would need to adapt any of these standardised assessment methods to meet the individual's abilities.

Family and carer involvement

There may be times where vicarious assessment is required, a member of staff or a carer may need to be interviewed as part of the assessment, with the person with learning disabilities remaining at the centre (NICE 2015). This could be because the individual has more severe learning disabilities or very pronounced communication problems. Family 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 ill-health (NICE 2016). Interviewing others in this way can also cause problems that may hinder the assessment process. High staff turnover means any new member of staff that is interviewed may have known the individual for a short space of time and have an incomplete knowledge of them (NICE 2016). This can lead to difficulties in identifying changes over time. In addition to this, is the high use of agency staff who may have only worked with someone on a few occasions. It is important to ascertain the level of knowledge a member of staff has about someone when taking any information from them. Other issues can occur if staff teams do not want to appear to be failing so paint a more positive picture, conversely, if someone is trying to obtain additional funding or services they may exaggerate.

Another factor that needs to be considered when interviewing staff is confirmation bias, this can occur when a member of staff has decided on a diagnosis and then looks for evidence to support this. For example, a member of staff decides that an individual that they support has dementia and then note any behaviour that may confirm this, ignoring other behaviours. If a third party is present at an interview, it is important to check with the individual with learning disabilities that they want someone else there because this could cause more caged answers. If there is a third party at the interview, it is important not to speak over the person with learning disabilities and just focus on this carer.

Assessment tools can also assist in the assessment process, either for use with person directly or with carers. NICE (2016) recommends the use of assessment tools that have been developed or adapted for people with learning disabilities, some are listed in the resources section of this article. The outcome obtained from using assessment tools not adapted or developed for people with learning disabilities needs to be interpreted with caution. There are evaluations of assessment tools for people with intellectual disabilities (Hobden and LeRoy 2008; Mohr and Costello 2009), although these reviews are now dated and there have been developments during this time.

Time Out Activity 3:

How is NICE (2016) Mental health problems in people with learning disabilities: prevention, assessment, and management – NG54 https://www.nice.org.uk/guidance/ng54 applied to practice where you work? What barriers are there to it being applied? How can these be overcome?

Strategies to support effective communication

Some people with learning disabilities have difficulties using expressive and receptive language so strategies can be used to support them. They include communication systems like Makaton, Picture Exchange Communication System (PECS), easy read symbols, speech and language therapy involvement, communication passports, Books Beyond Words, communications boards, Talking Mats, social stories, objects and images.

Time Out Activity 4:

From your experience of assessing people with learning disabilities, list the essential skills required for an effective assessment. Which ones of these are you best at? Where might you need additional support? And where could this support be found?

The role of the nurse

Learning disabilities nurses can screen referrals and gather information about the individual on how they communicate. They could complete the nursing assessment and risk assessment using a biopsychosocial approach (Sheerin et al 2019). They can establish the person's history from the individual and people who know them well, and refer for specialist assessment, for example, clinical psychologist, psychiatrist; and ensure shared decision making is used. Learning disabilities nurses can support access to mental health services and educate other practitioners on the distinct needs of people with learning disabilities. Learning disabilities nurses ensure reasonable adjustments are implemented when other professionals are assessing people with learning disabilities (Mafuba et al 2020). Whilst assessing for mental health problems learning disabilities nurses should also consider risk (NICE 2016). These include risk to self and others; of neglect; vulnerability and exploitation; triggers, causal and maintenance factors; and consider if safeguarding arrangements need to be implemented (Mafuba et al 2020). Assessing mental health problems in people with learning disabilities, even with additional awareness of communication problems is challenging. Learning disabilities nurses may be better suited to identify subtle changes over time and be able to liaise with significant others in an individual with learning disabilities' life. This may be particular pertinent when assessing people with more severe learning disabilities or more pronounced communication issues. There may be a greater reliance on looking for slight behavioural changes that could indicate the signs and symptoms of a mental health problem.

Time Out Activity 5:

Can you reflect on your experiences of working within a multidisciplinary team – what have you been able to explain to others to assist in assessment? What have you learned from about assessment from other professionals?

Overcoming communication problems – to go in breakout box

Dos

- Establish if the individual being assessed has a preferred communication strategy or any form of communication passport.
- Use active verbs and stay in the present tense. For example, "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. Instead of saying '*your appointment is with Jane, it starts at nine o'clock and it will last thirty minutes*', consider '*your appointment is with Jane, your appointment starts at nine o'clock and your appointment will last thirty minutes*'.
- Use lay terms in place of medical jargon and ensure terms are understood by the individual too.
- Once a word has been used to describe something, continue to use this word from then on.
- 'Anchor events' can help someone with recalling information from the past (Mindham and Espie, 2003). Instead of asking '…. *how long have you been having these thoughts?*' an anchor event can be inserted as an aide-memoire, for example, '…. *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?*'
- As well as the assessor leading the person to giving a 'yes' or 'no' answer, an individual may automatically answer 'yes' to every question regardless of the answer, similarly they may give a 'no' to every question. This is sometimes referred to as 'yea-saying' or 'nay-saying'. To confirm response given, subtly reverse the question.
- Be aware of the power dynamic. Consider whether a uniform, name badge or formal dress might be intimidating, and an appropriate venue.
- Use assessment tools specifically designed for people with learning disabilities (NICE 2016). They assist in framing the questions and have accompanying images to assist.
- Consider guidance on communicating with people with learning disabilities from Mencap (2018), the government's accessible information standards (NHS England 2015), the Royal College of Speech and Language Therapists and advice on communicating with people with learning disabilities who may have mental health problems (Hardy et al 2013).

Don'ts

- Do not use abstract concepts, consider concrete ones. For example, asking if someone is 'feeling low' could be difficult. Consider "*are you crying more?*" is easier to answer because the person can identify this concrete sensation rather than the abstract concepts that may have caused the crying.
- Avoid lengthy sentences, make them short and concise. Ask one question at a time and wait for the answer, do not stack multiple questions.
- Avoid use of double negatives. An example could be '…. *call me Monday to Friday*' rather than '…. *do not call me on weekends, when I will not be at work*'
- Avoid using leading questions, which may urge the individual to say yes or no. '…. *your mum has said that you've been feeling low, is this right?*', this suggests an answer of 'yes'. And '*You haven't been drinking alcohol, have you?*' – suggests an answer of 'no'
- Avoid offering lengthy options as the individual may choose the last item on a long list as it is the freshest thing on their mind. Offer two choices at a time, let the individual select one of these and then offer a new option, along with their last preferred choice. This means the individual is only ever choosing from two options.

Conclusions

People with learning disabilities experience mental health problems just like other people yet it is difficult and complex to assess and diagnose. Communication difficulties experienced by people with learning disabilities affect the assessment process. There is a need to engage effective communication strategies and consider using adapted assessment tools when assessing people with learning disabilities with mental ill-health to improve the chances of accurate outcomes. Learning disabilities nurses are well placed to ensure mental health assessments in people with learning disabilities are appropriately and efficiently completed and by enhancing their communication skills the chances of accurate diagnosis will be improved.

Time Out Activity 6:

Now that you have completed the article, reflect on your practice in this area and consider writing a reflective account. See "Write a reflective account" at https://rcni.com/nursing-standard/revalidation/reflective-accounts/write-a-reflective-account-90981

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Useful Resources:

- Makaton: https://makaton.org/
- Books Beyond Words: https://booksbeyondwords.co.uk/
- Foundation for People with Learning Disabilities – Easy Read: https://www.learningdisabilities.org.uk/learning-disabilities/a-to-z/e/easy-read#:~:text='Easy%20read'%20refers%20to%20the,affecting%20how%20they%20process%20information.
- NHS England - Easy read information: https://www.england.nhs.uk/learning-disabilities/about/resources/er/
- Easy Health: https://www.easyhealth.org.uk/
- National Institute for Health and Care Excellence (NICE) guideline [NG54]: Mental health problems in people with learning disabilities: prevention, assessment and management: https://www.nice.org.uk/guidance/ng54/chapter/Recommendations#assessment

- NHS England guidance on accessible information https://www.england.nhs.uk/about/equality/equality-hub/patient-equalities-programme/equality-frameworks-and-information-standards/accessibleinfo/
- Commonly used mental health assessment tools applicable to people with learning disabiltiies used in the UK:
    - The Glasgow Depression Scale ofr people with learning disabilities
    - The Glasgow Anxiety Scale for people with intellectual disabilities
    - The PAS-ADD / Moss-PAS(ID) family of instruments
    - Dementia Screening Questionnaire for Individuals with Intellectual Disabilities.
- Link to review of mental health assessment tools for assessing people with learning disabilities: https://ddi.wayne.edu/publications/assessing_mental_health_concerns_in_adults_with_id_2008.pdf
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