# Appendix T: Nominal group technique questionnaires

[T.1 Assessment 3](#_Toc444271794)

[A.1.1 Case id 3](#_Toc444271795)

[A.1.1.1 Round 1 3](#_Toc444271796)

[A.1.1.2 Round 2 6](#_Toc444271797)

[A.1.2 Brief (initial) assessment 9](#_Toc444271798)

[A.1.2.1 Round 1 9](#_Toc444271799)

[A.1.2.2 Round 2 25](#_Toc444271800)

[A.1.3 Comprehensive assessment 28](#_Toc444271801)

[A.1.3.1 Round 1 28](#_Toc444271802)

[T.2 Psychological interventions 46](#_Toc444271803)

[T.2.1 Round 1 46](#_Toc444271804)

[T.2.2 Round 2 (Mild to moderate) 53](#_Toc444271805)

[T.2.3 Round 2 (Severe to Profound) 61](#_Toc444271806)

[T.3 Pharmacological interventions 63](#_Toc444271807)

[T.3.1 Round 1 63](#_Toc444271808)

[T.4 Other interventions 68](#_Toc444271809)

[T.4.1 Social and environmental interventions 68](#_Toc444271810)

[T.4.1.1 Round 1 68](#_Toc444271811)

[T.4.1.2 Round 2 71](#_Toc444271812)

[T.4.2 Occupational interventions 75](#_Toc444271813)

[T.4.2.1 Round 1 75](#_Toc444271814)

[T.5 Organisation and service delivery 78](#_Toc444271815)

[T.5.1 Round 1 78](#_Toc444271816)

[T.5.2 Round 2 89](#_Toc444271817)

* 1. Assessment

## A.1.1 Case ID

### A.1.1.1 Round 1

MHLD CONSENSUS QUESTIONNAIRE (case identification)

|  |  |
| --- | --- |
| Name: | Date: |

**Case identification: completed in any setting by anyone (including family or carers) to determine if someone should have a formal assessment for a mental health problem**

The literature review did not find evidence on the **identification of mental health problems in people with learning disabilities** that was of sufficient methodological quality, as outlined in the review protocols, to include in the review. Therefore statements regarding case identification have been developed to be assessed by the group through the nominal group technique.

Statements are split into two sections: general principles for case identification (p. 2-3) and action following possible identification of a mental health problem (p. 3-4).

Please ensure you have checked both sides of each sheet of paper, so that no items are missed.

For each of the statements please indicate your agreement as to their appropriateness and utility by circling one number in each row. The scale works as follows:

**Number 1**: Strongly disagree with this adaptation.

**Number 5**: Neither agree nor disagree.

**Number 9**: Strongly agree that this is a useful and appropriate adaptation.

There is also room to provide comments, if you wish.

|  |
| --- |
| **Case identification: general principles** |
| **Statements relating to general principles for case identification of mental health problems in people with learning disabilities.** | **Scale** |
| **Strongly disagree** |  | **Strongly agree** |
| 1. All staff who come into contact with people with a learning disability should understand the different ways in which mental health problems may develop and present (compared with in people without a learning disability).
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. For a person with a mild learning disability, the use of identification questions recommended in relevant NICE guidelines for common mental health problems should be considered.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. For a person with a mild learning disability, minor adaptations to the identification questions recommended in relevant NICE guidelines for common mental health problems should be considered, taking into account the individual’s level of comprehension and abilities.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. Questions designed to identify mental health problems in people with a learning disability should focus not only on signs and symptoms but also on changes in behaviour.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. Changes in behaviour that could indicate the presence of a mental health problem in a person with a learning disability include behaviour that challenges, social withdrawal, avoidance and agitation.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. In people with a learning disability increased difficulties in communication may indicate the presence of a mental health problem.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. When determining if a mental health problem is present in a person with a learning disability, focusing on what has changed for the individual at the personal or environmental level is important.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. Records and relevant outcome or behavioural data should be reviewed to help determine if a mental health problem might be present.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. Prospective monitoring should be considered to help determine if a mental health problem might be present.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. A person with a learning disability should be asked direct questions about their current thoughts and feelings, and whether anything has been bothering them recently.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. Family members or carers should be asked if recent changes in behaviour are accompanied by a person changes in mood or anxiety levels.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. Family members, carers and support workers who are in contact with people with a severe or profound learning disability should be aware that changes in the persons’ behaviour, such as phobic or avoidant behaviour, might indicate the development of a mental health problem.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |

|  |
| --- |
| **Action following possible identification of a mental health problem** |
| **Statements relating to the action following the possible identification of a mental health problems in people with learning disabilities.** | **Scale** |
| **Strongly disagree** |  |  |  | **Strongly agree** |
| 1. If a mental health problem is suspected by a staff member, they should conduct an assessment if they are competent to do so.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. If a mental health problem is suspected by a person who is not competent to complete an assessment, the person with a learning disability should be referred to a competent professional for an assessment.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. The person with a learning disability or their family or carers should be offered support and advice in obtaining a mental health assessment for the person with a learning disability.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. All health and social care workers conducting a mental health assessment should be aware of the nature of the person’s learning disability, their strengths and needs and their current care.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. People with a suspected psychotic disorder should be referred to a psychiatrist with experience or expertise of treating mental health problems in people with a learning disability.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |

### A.1.1.2 Round 2

MHLD CONSENSUS QUESTIONNAIRE (case identification)

|  |  |
| --- | --- |
| Name: | Date: |

**Case identification: completed in any setting by anyone (including family or carers) to determine if someone should have a formal assessment for a mental health problem**

The literature review did not find evidence on the **identification of mental health problems in people with learning disabilities** that was of sufficient methodological quality, as outlined in the review protocols, to include in the review. Therefore statements regarding case identification have been developed to be assessed by the group through the nominal group technique.

Statements are split into two sections: general principles for case identification (p. 2-3) and action following possible identification of a mental health problem (p. 3-4).

Please ensure you have checked both sides of each sheet of paper, so that no items are missed.

For each of the statements please indicate your agreement as to their appropriateness and utility by circling one number in each row. The scale works as follows:

**Number 1**: Strongly disagree with this adaptation.

**Number 5**: Neither agree nor disagree.

**Number 9**: Strongly agree that this is a useful and appropriate adaptation.

There is also room to provide comments, if you wish.

|  |
| --- |
| **Case identification: general principles** |
| **Statements relating to general principles for case identification of mental health problems in people with learning disabilities.** | **Scale** |
| **Strongly disagree** |  | **Strongly agree** |
| 1. All staff who come into contact with people with a learning disability should understand the different ways in which mental health problems may develop and present (compared with in people without a learning disability).
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. For a person with a mild learning disability, the use of identification questions recommended in relevant NICE guidelines for common mental health problems should be considered.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. For a person with a mild learning disability, minor adaptations to the identification questions recommended in relevant NICE guidelines for common mental health problems should be considered, taking into account the individual’s level of comprehension and abilities.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. Questions designed to identify mental health problems in people with a learning disability should focus not only on signs and symptoms but also on changes in behaviour.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. Changes in behaviour that could indicate the presence of a mental health problem in a person with a learning disability include behaviour that challenges, social withdrawal, avoidance and agitation.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. In people with a learning disability increased difficulties in communication may indicate the presence of a mental health problem.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. When determining if a mental health problem is present in a person with a learning disability, focusing on what has changed for the individual at the personal or environmental level is important.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. Records and relevant outcome or behavioural data should be reviewed to help determine if a mental health problem might be present.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. Prospective monitoring should be considered to help determine if a mental health problem might be present.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. A person with a learning disability should be asked direct questions about their current thoughts and feelings, and whether anything has been bothering them recently.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. Family members or carers should be asked if recent changes in behaviour are accompanied by a person changes in mood or anxiety levels.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. Family members, carers and support workers who are in contact with people with a severe or profound learning disability should be aware that changes in the persons’ behaviour, such as phobic or avoidant behaviour, might indicate the development of a mental health problem.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |

|  |
| --- |
| **Action following possible identification of a mental health problem** |
| **Statements relating to the action following the possible identification of a mental health problems in people with learning disabilities.** | **Scale** |
| **Strongly disagree** |  |  |  | **Strongly agree** |
| 1. If a mental health problem is suspected by a staff member, they should conduct an assessment if they are competent to do so.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. If a mental health problem is suspected by a person who is not competent to complete an assessment, the person with a learning disability should be referred to a competent professional for an assessment.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. The person with a learning disability or their family or carers should be offered support and advice in obtaining a mental health assessment for the person with a learning disability.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. All health and social care workers conducting a mental health assessment should be aware of the nature of the person’s learning disability, their strengths and needs and their current care.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. People with a suspected psychotic disorder should be referred to a psychiatrist with experience or expertise of treating mental health problems in people with a learning disability.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |

## A.1.2 Brief (initial) assessment

### A.1.2.1 Round 1

MHLD CONSENSUS QUESTIONNAIRE (brief assessment)

|  |  |
| --- | --- |
| Name: | Date: |

The literature review did not find evidence on adaptations to **brief assessment of mental health problems in people with learning disabilities** that was of sufficient methodological quality, as outlined in the review protocols, to include in the review. Therefore statements regarding adaptations to brief assessment of mental health for people with LD have been developed to be assessed by the group through the nominal group technique. We have also developed statements for comprehensive assessment procedures, however these are presented within another document for the sake of brevity. There is some duplication between the two questionnaires; this is intentional. At times statements may read very similarly, again this is intentional, and you will find that there is a slight difference of emphasis in these cases.

Statements are split into four sections, each containing a number of sub-sections; Principles of a brief assessment of mental health problems in people with LD (Principles p2-3, collaborative approach p3-4, accessibility p4-5 and rigorous assessments p6); Purpose of a brief assessment (Purpose p6-7, Risk assessment p7-8, formulation p8); Structure of a brief assessment (Staff conducting the assessment p8-9, involving service users p9-10, data sources p10-11) and Outcomes of a brief assessment (Outcomes p11, the care plan p11-12, outcomes monitoring p12-13). Please ensure you have checked both sides of each sheet of paper, so that no items are missed.

For each of the statements please indicate your agreement as to their appropriateness and utility by circling one number in each row. The scale works as follows:

**Number 1**: Strongly disagree with this adaptation.

**Number 5**: Neither agree nor disagree.

**Number 9**: Strongly agree that this is a useful and appropriate adaptation.

There is also room to provide comments, if you wish.

|  |
| --- |
| **Principles of a brief assessment** |
| **Statements relating to general principles of adaptations to brief assessment of mental health problems in people with learning disabilities.** | **Scale** |
| **Strongly disagree** |  | **Strongly agree** |
| 1. A brief assessment should be conducted based on an understanding of the context and setting in which it is undertaken.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. A brief assessment should take into account symptom severity, the service user’s understanding of the problem, degree of distress and functional impairment.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. A brief assessment should draw on those information sources that directly relate to the purpose of the assessment.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. The content and structure of the brief assessment should be adapted to the severity of the learning which a person has.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. A brief assessment should consider the misuse of drugs or alcohol as a potential problem in itself and also as a contributory factor in other disorders.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. A brief assessment should have an identified outcome.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. A brief assessment should be repeated if further relevant information emerges.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. A brief assessment should seek to identify service users’ strengths.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. When conducting a brief assessment, staff should seek to understand how the physical and social environment may contribute to the development or maintenance of the issues that are the focus of the assessment.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. A brief assessment with a person with a learning disability should consider any neurological or physical health problems or genetic syndromes that may influence the development or presentation of mental health problems.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. Service users, and if appropriate family members, carers or support workers, should be provided with a summary of the brief assessment, including any potential implications.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. Confidentiality (and its limits) should be explained clearly to the service user, and family members or carers as appropriate, before the assessment.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. Staff conducting a brief assessment should be aware of diagnostic overshadowing (that a physical health problem or cognitive impairment may mask an underlying mental health problem).
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. Staff conducting a brief assessment should be aware of the likely presentations of mental health disorders associated with specific disorders or syndrome which causal of the learning disability.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. Staff conducting a brief assessment should be aware of the impact of neurodevelopmental disorders on the presentations of mental health symptoms.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. Staff conducting a brief assessment should be aware that what presents as a mental health problem might be caused by an underlying physical health problem.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |

|  |
| --- |
| **Principles of a brief assessment: Collaborative approach** |
| **Statements relating to the collaborative approach that should be taken during brief assessment of mental health problems in people with learning disabilities.** | **Scale** |
| **Strongly disagree** |  |  |  | **Strongly agree** |
| 1. A brief assessment should be undertaken in a collaborative manner and maximise the contribution of all people involved.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. Staff conducting a brief assessment should consider involving a family member, partner, carer or advocate to support the service user in order to facilitate the collaborative nature of the assessment.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. Families and carers should be included in decision making if the service user agrees, and this is deemed appropriate.
 |  |  |  |  |  |  |  |  |  |
| Comments: |
| 1. At the beginning of a brief assessment the preferred format for feedback about the outcome of the assessment and formulation should be discussed with the service user.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. Staff conducting a brief assessment should acknowledge and identify the reasons for any significant differences between their views and the views of the service user about the issues that are the focus of the assessment.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. Staff should discuss any queries or concerns that the service user may have regarding the assessment process and ensure they feel comfortable about asking questions.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. A collaborative formulation should acknowledge and address the factors that the service user considers relevant.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |

|  |
| --- |
| **Principles of a brief assessment: Accessible assessments** |
| **Statements relating to adaptations designed to increase accessibility of brief assessment of mental health problems in people with learning disabilities.** | **Scale** |
| **Strongly disagree** |  | **Strongly agree** |
| 1. Staff conducting the brief assessment should ensure the environment for the assessment is free from unnecessary distractions including noise and visual stimuli.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. Staff conducting the brief assessment should ensure that the assessment is adapted to the person with a learning disability, including their cognitive and communication abilities and any other specific needs (including visual, hearing and other sensory impairments).
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. The structure and pace of a brief assessment should be tailored to the service user’s level of comprehension.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. The structure and pace of a brief assessment should be tailored to the person’s immediate levels of stress and capacity to deal with the emotional content of the assessment.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. Staff conducting the brief assessment should use clear and unambiguous questions, employ aids to facilitate communication, ensure brevity, and regularly check understanding.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. Tools such as a visual timeline should be used to explain the assessment process and be referred to throughout the brief assessment.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. The presentation of information should be tailored to the ability of the service user to comprehend the purpose of the brief assessment.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. The pace and content of a brief assessment should be adjusted to be in line with the person’s immediate levels of stress and capacity to deal with the emotional content of the assessment.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. A brief assessment should be flexible and responsive to new information and concerns.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. Staff conducting a brief assessment should be competent in a range of communication skills, including the assessment of people with communication difficulties and sensory impairments.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. Staff conducting a brief assessment should be aware of the impact of neurodevelopmental problems on the presentations of mental health problems.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. Staff conducting a brief assessment should be aware of the impact of neurodevelopmental problems on the ability of an individual to participate in an assessment and adjust the structure and content of the assessment as necessary.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |

|  |
| --- |
| **Principles of a brief assessment: Rigorous assessments** |
| **Statements relating to the rigorous approach that should be taken during brief assessment of mental health problems in people with learning disabilities.** | **Scale** |
| **Strongly disagree** |  |  |  | **Strongly agree** |
| 1. A brief assessment may use validated tools relevant to the disorder(s) or problem(s) being assessed.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. Staff conducting a brief assessment should maintain a record of the content and outcome of the assessments.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |

|  |
| --- |
| **Purpose of a brief assessment** |
| **Statements relating to purpose of a brief assessment of mental health problems in people with learning disabilities.** | **Scale** |
| **Strongly disagree** |  |  |  | **Strongly agree** |
| 1. A brief assessment should seek to increase understanding of a potential problem, and, where necessary, to describe the problem and develop a plan of action to address the problem and any needs associated with it.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. The purpose of the brief assessment, and how the data may be used, should be made clear to all people involved in the assessment, including other staff members.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. A brief assessment should take into account symptom severity, the service user’s understanding of the problem, degree of distress and functional impairment.
 |  |  |  |  |  |  |  |  |  |
| Comments: |
| 1. A brief assessment should focus on specific areas of need, in agreement with the service user, family members or carers as appropriate.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. Identifying the presence or otherwise of a mental health diagnosis or problem specification may be an important component of a brief assessment.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. A brief assessment should provide relevant information on the nature, duration and severity of the presenting disorder or problem.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. A brief assessment should consider the consequence of any possible or established coexisting mental or physical health problems.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |

|  |
| --- |
| **Purpose of a brief assessment: risk assessment and management** |
| **Statements relating to adaptations to risk assessment and management during brief assessment of mental health problems in people with learning disabilities.** | **Scale** |
| **Strongly disagree** |  | **Strongly agree** |
| 1. In any brief assessment the decision to undertake a risk assessment should be considered.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. A risk assessment should form part of any brief assessment.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. Vulnerability to exploitation should be assessed as part of a brief assessment.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. Safeguarding concerns should be assessed as part of a brief assessment.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. Risk to self (self-harm, self-neglect) should be assessed as part of a brief assessment.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. Risk to others (including aggression, violence and sexual offending) should be assessed as part of a brief assessment.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. Risk assessment should assess the nature and severity of any behaviours, potential triggers and maintaining factors.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. Risk assessment should assess the likelihood, imminence and severity of events.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. Risk assessment should involve a consideration of demographic, psychological, social and historical factors.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. Risk assessment should be informed by knowledge of the service user and their social context.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. Risk assessment should always lead to the development of a risk management plan.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. A risk management plan should identify interventions and protective factors that may reduce risk.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. The risk management plan should be communicated to relevant services or agencies.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |

|  |
| --- |
| **Purpose of a brief assessment: formulation** |
| **Statements relating to formulation during brief assessment of mental health problems in people with learning disabilities.** | **Scale** |
| **Strongly disagree** |  |  |  | **Strongly agree** |
| 1. A brief assessment should involve a formulation of the service user’s identified problems.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. A formulation should provide a shared understanding of the nature of any problems, and the factors leading to their development and maintenance.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. A formulation should provide a shared understanding of the focus and potential impact of any interventions and the barriers to delivering those interventions.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. A formulation should consider any risk factors and the impact of the social and physical environment.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |

|  |
| --- |
| **Structure of a brief assessment: Staff conducting the assessment** |
| **Statements relating to the staff who should participate in a brief assessment of mental health problems in people with learning disabilities.** | **Scale** |
| **Strongly disagree** |  |  |  | **Strongly agree** |
| 1. A brief assessment should be conducted by a clinician with specialist knowledge and understanding of mental health difficulties in people with a learning disability.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. A brief assessment should be conducted by a clinician with specialist knowledge and understanding of mental health problems in people with a learning disability in collaboration with other professionals with relevant expertise.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. Staff involved in a brief assessment should be trained and competent in using a range of assessment tools and methods relevant to people with a learning disability and a mental health problem.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. Staff involved in a brief assessment should be trained and competent in using routine outcome measures relevant to people with a learning disability and a mental health problem.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. Staff conducting a brief assessment should have knowledge of diagnostic classification systems.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. Staff conducting a brief assessment should have knowledge of diagnostic classification systems, their limitations and specific concerns such as diagnostic overshadowing relevant to this population.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. Staff should make use of reliable pre-existing information to avoid duplicating areas of assessment that have already been undertaken.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |

|  |
| --- |
| **Structure of a brief assessment: Involving service users, families and carers in the assessment** |
| **Statements relating to who else should be involved in a brief assessment of mental health problems in people with learning disabilities.** | **Scale** |
| **Strongly disagree** |  |  |  | **Strongly agree** |
| 1. A brief assessment should elicit service users’ views and corroborate these with families and carers.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. A brief assessment should elicit service users’ views and corroborate these with professionals involved in the person’s care and other informants.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. A brief assessment should consider the views of other people relevant to the care of the service user, including families, carers and other staff members, with permission and where appropriate.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. The person with a learning disability should be offered the opportunity to speak to the clinician alone, in order to elicit any concerns that they are uncomfortable sharing in front of family members or carers, including safeguarding concerns.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. A brief assessment should, with the service user’s agreement, gather information from relevant data sources and informants who know the service user well.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. A brief assessment should corroborate information with families and carers, if agreed by the service user.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |

|  |
| --- |
| **Structure of a brief assessment: Data sources** |
| **Statements relating to data sources for a brief assessment of mental health problems in people with learning disabilities.** | **Scale** |
| **Strongly disagree** |  |  |  | **Strongly agree** |
| 1. The impact of environmental factors on data availability and reliability should be considered in a brief assessment.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. A brief assessment should evaluate and integrate information from relevant sources, including interviews with service users and others, observations, standardised assessments, psychometric assessments and clinical records.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. A brief assessment should consider whether, and how, the service user’s behaviour and functioning changes across different settings.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. A brief assessment should review relevant history and past behaviour.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. Staff conducting a brief assessment should be able to appraise the reliability and validity of data sources.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. Staff conducting a brief assessment should use measures that have been developed in, or adapted for, people with a learning disability.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |

|  |
| --- |
| **Outcomes of a brief assessment** |
| **Statements relating to outcomes from a brief assessment of mental health problems in people with learning disabilities.** | **Scale** |
| **Strongly disagree** |  |  |  | **Strongly agree** |
| 1. Staff conducting a brief assessment should agree with the service user appropriate outcome measures used in evaluating any care plan.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. An outcome of a brief assessment should be the identification of realistic and optimistic short and medium-term goals.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. An outcome of a brief assessment should be the identification of realistic and optimistic long-term goals.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. Goals for interventions should be prioritised and start with areas most likely to be amenable to change.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. When making a referral, sufficient information should be provided to allow the service to make an informed decision about how to proceed.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |

|  |
| --- |
| **Outcomes of a brief assessment: The care plan** |
| **Statements relating to the care plan that should be produced from a brief assessment of mental health problems in people with learning disabilities.** | **Scale** |
| **Strongly disagree** |  | **Strongly agree** |
| 1. A care plan should be informed by the brief assessment, the formulation that emerges from this and the service user’s goals.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. Initial care plans appropriate for the current setting should be developed as soon as possible following assessment.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. Initial care plans should be communicated in the most appropriate way to the service user and all services involved in their care in a timely manner.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. The care plan should be developed collaboratively with the service user and, if they agree, their family or carers.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. If the care plan involves a family member, partner, carer or advocate, their involvement should be used to help explain feedback from the assessment to the service user.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. The care plan should identify appropriate evidence-based interventions.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. The care plan should include any necessary adaptations to the social or physical environment.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. The care plan should take into account the needs of families and carers.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. Risk and crisis management plans should be incorporated into the care plan.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. The care plan should identify the roles and responsibilities of all people involved in the service user’s care.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |

|  |
| --- |
| **Outcomes of a brief assessment: Monitoring of individualised and standard outcomes** |
| **Statements relating to monitoring of outcomes from a brief assessment of mental health problems in people with learning disabilities.** | **Scale** |
| **Strongly disagree** |  |  |  | **Strongly agree** |
| 1. A brief assessment should inform necessary routine outcome monitoring including changes in symptoms and functioning.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. The care plan should establish a timetable to review whether goals have been met by an agreed time or point in treatment.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. Outcome measures should be selected that are designed to detect changes in the areas targeted by interventions.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. Systems should be developed for routine data sharing between other health and social care services and agencies, to reduce repetition in the assessment process.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |

### A.1.2.2 Round 2

MHLD CONSENSUS QUESTIONNAIRE (brief assessment)

|  |  |
| --- | --- |
| Name: | Date: |

The following statements have had moderate agreement on round one and have been re-worded for re-rating.

Statements are split into 3 sections: Purpose of a brief assessment (p. 2); Structure of a brief assessment (Staff conducting the assessment p2,) and Outcomes of a brief assessment (p. 2). Please ensure you have checked both sides of each sheet of paper, so that no items are missed.

For each of the statements please indicate your agreement as to their appropriateness and utility by circling one number in each row. The scale works as follows:

**Number 1**: Strongly disagree with this adaptation.

**Number 5**: Neither agree nor disagree.

**Number 9**: Strongly agree that this is a useful and appropriate adaptation.

There is also room to provide comments, if you wish.

|  |
| --- |
| **Purpose of a brief assessment** |
| **Statements relating to purpose of a brief assessment of mental health problems in people with learning disabilities.** | **Scale** |
| **Strongly disagree** |  |  |  | **Strongly agree** |
| 1. A brief assessment should be broad with the aim of identifying areas to be addressed in more detail as part of a comprehensive assessment.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |

|  |
| --- |
| **Structure of a brief assessment: Staff conducting the assessment** |
| **Statements relating to the staff who should participate in a brief assessment of mental health problems in people with learning disabilities.** | **Scale** |
| **Strongly disagree** |  |  |  | **Strongly agree** |
| 1. A brief assessment should be conducted by a professional with knowledge and understanding of mental health difficulties in people with a learning disability.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. A brief assessment should be conducted by a professional with knowledge and understanding of mental health problems in people with a learning disability in collaboration with other professionals with relevant expertise.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. Staff conducting a brief assessment should have knowledge of diagnostic classification systems.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |

|  |
| --- |
| **Outcomes of a brief assessment** |
| **Statements relating to outcomes from a brief assessment of mental health problems in people with learning disabilities.** | **Scale** |
| **Strongly disagree** |  |  |  | **Strongly agree** |
| 1. Staff conducting a brief assessment should agree with the person being assessed and other involved family members or carers, if needed, appropriate outcome measures used in evaluating any care plan.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |

## A.1.3 Comprehensive assessment

### A.1.3.1 Round 1

MHLD CONSENSUS QUESTIONNAIRE (comprehensive assessment)

|  |  |
| --- | --- |
| Name: | Date: |

The literature review did not find evidence on adaptations to **comprehensive assessment of mental health problems in people with learning disabilities** that was of sufficient methodological quality, as outlined in the review protocols, to include in the review. Therefore statements regarding adaptations to comprehensive assessment have been developed to be assessed by the group through the nominal group technique. We have also developed statements for brief assessment procedures, however these are presented within another document for the sake of brevity. There is some duplication between the two questionnaires; this is intentional. At times statements may read very similarly, again this is intentional, and you will find that there is a slight difference of emphasis in these cases.

Statements are split into four sections, each containing a number of sub-sections; Principles of a comprehensive assessment of mental health problems in people with LD (Principles p2-3, collaborative approach p4, accessibility p5-6 and rigorous assessments p6); Purpose of a comprehensive assessment (Purpose p7, Risk assessment p8-9, formulation p9); Structure of a comprehensive assessment (Staff conducting the assessment p9-10, involving service users p10-11, data sources p11-12) and Outcomes of a comprehensive assessment (Outcomes p12, the care plan p13-14, referrals p14 and outcomes monitoring p14). Please ensure you have checked both sides of each sheet of paper, so that no items are missed.

For each of the statements please indicate your agreement as to their appropriateness and utility by circling one number in each row. The scale works as follows:

**Number 1**: Strongly disagree with this adaptation.

**Number 5**: Neither agree nor disagree.

**Number 9**: Strongly agree that this is a useful and appropriate adaptation.

There is also room to provide comments, if you wish.

|  |
| --- |
| **Principles of a comprehensive assessment** |
| **Statements relating to general principles of adaptations to comprehensive assessment of mental health problems in people with learning disabilities.** | **Scale** |
| **Strongly disagree** |  | **Strongly agree** |
| 1. A comprehensive assessment should be conducted based on an understanding of the context and setting in which it is undertaken.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. A comprehensive assessment should take into account symptom severity, the service user’s understanding of the problem, degree of distress and functional impairment.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. A comprehensive assessment should draw on a wide range of information sources.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. The content and structure of the comprehensive assessment should be adapted to the severity of the learning which a person has.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. A comprehensive assessment should consider the misuse of drugs or alcohol as a potential problem in itself and also as a contributory factor in other disorders.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. A comprehensive assessment should have an identified outcome.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. A comprehensive assessment should be reviewed in line with an agreed timescale.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. A comprehensive assessment should be revised when further relevant information emerges.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. A comprehensive assessment should seek to identify service users’ strengths.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. When conducting a comprehensive assessment, staff should seek to understand how the physical and social environment may contribute to the development or maintenance of the issues that are the focus of the assessment.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. A comprehensive assessment with a person with a learning disability should take into account any neurological or physical health problems or genetic syndromes that may influence the development or presentation of mental health problems.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. Service users, and if appropriate family members, carers or support workers, should be provided with a summary of the comprehensive assessment, including any potential implications.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. Service users, and if appropriate family members, carers or support workers, should be offered be given a further opportunity (such as a follow-up appointment) to discuss the outcomes and implications of the comprehensive assessment.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. Confidentiality (and its limits) should be explained clearly to the service user, and family members or carers as appropriate, before the assessment.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. Staff conducting a comprehensive assessment should be aware of diagnostic overshadowing (that a physical health problem or cognitive impairment may mask an underlying mental health problem).
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. Staff conducting a comprehensive assessment should be aware of the likely presentations of mental health disorders associated with specific disorders or syndrome which causal of the learning disability.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. Staff conducting a comprehensive assessment should be aware of the impact of neurodevelopmental disorders on the presentations of mental health symptoms.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. Staff conducting a comprehensive assessment should be aware that what presents as a mental health problem might be caused by an underlying physical health problem.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |

|  |
| --- |
| **Principles of a comprehensive assessment: Collaborative approach** |
| **Statements relating to the collaborative approach that should be taken during comprehensive assessment of mental health problems in people with learning disabilities.** | **Scale** |
| **Strongly disagree** |  |  |  | **Strongly agree** |
| 1. A comprehensive assessment should be undertaken in a collaborative manner and maximise the contribution of all people involved.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. Staff conducting a comprehensive assessment should consider involving a family member, partner, carer or advocate to support the service user in order to facilitate the collaborative nature of the assessment.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. Families and carers should be included in decision making if the service user agrees, and this is deemed appropriate.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. At the beginning of a comprehensive assessment the preferred format for feedback about the outcome of the assessment and formulation should be discussed with the service user.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. How information about the service user will be shared with families, carers and other staff members should be negotiated with service users and carers.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. Staff conducting a comprehensive assessment should acknowledge and identify the reasons for any significant differences between their views and the views of the service user about the issues that are the focus of the assessment.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. Staff should discuss any queries or concerns that the service user may have regarding the assessment process and ensure they feel comfortable about asking questions.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. A collaborative formulation should acknowledge and address the factors that the service user considers relevant.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |

|  |
| --- |
| **Principles of a comprehensive assessment: Accessible assessments** |
| **Statements relating to adaptations designed to increase accessibility of comprehensive assessment of mental health problems in people with learning disabilities.** | **Scale** |
| **Strongly disagree** |  | **Strongly agree** |
| 1. Staff conducting the comprehensive assessment should ensure the environment for the assessment is free from unnecessary distractions including noise and visual stimuli.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. Staff conducting the comprehensive assessment should ensure that the assessment is adapted to the person with a learning disability, including their cognitive and communication abilities and any other specific needs (including visual, hearing and other sensory impairments).
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. The structure and pace of the comprehensive assessment should be tailored to the service user’s level of comprehension.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. The structure and pace of the comprehensive assessment should be tailored to the person’s immediate levels of stress and capacity to deal with the emotional content of the assessment.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. Staff conducting the comprehensive assessment should use clear and unambiguous questions, employ aids to facilitate communication, ensure brevity, and regularly check understanding.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. Tools such as a visual timeline should be used to explain the assessment process and be referred to throughout the comprehensive assessment.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. The presentation of information should be tailored to the ability of the service user to comprehend the purpose of the comprehensive assessment.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. The pace and content of a comprehensive assessment should be adjusted to be in line with the person’s immediate levels of stress and capacity to deal with the emotional content of the assessment.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. A comprehensive assessment should be flexible and responsive to new information and concerns.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. Staff conducting a comprehensive assessment should be competent in a range of communication skills, including the assessment of people with communication difficulties and sensory impairments.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. Staff conducting a comprehensive assessment should be aware of the impact of neurodevelopmental problems on the presentations of mental health problems.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. Staff conducting a comprehensive assessment should be aware of the impact of neurodevelopmental problems on the ability of an individual to participate in an assessment and adjust the structure and content of the assessment as necessary.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |

|  |
| --- |
| **Principles of a comprehensive assessment: Rigorous assessments** |
| **Statements relating to the rigorous approach that should be taken during comprehensive assessment of mental health problems in people with learning disabilities.** | **Scale** |
| **Strongly disagree** |  |  |  | **Strongly agree** |
| 1. A comprehensive assessment should use validated tools relevant to the disorder(s) or problem(s) being assessed.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. If tools have (not) been adapted specifically for use with a person with a learning disability, this should be taken into account in their interpretation.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. Staff conducting a comprehensive assessment should maintain a record of the content and outcome of the assessments.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |

|  |
| --- |
| **Purpose of a comprehensive assessment** |
| **Statements relating to purpose of a comprehensive assessment of mental health problems in people with learning disabilities.** | **Scale** |
| **Strongly disagree** |  |  |  | **Strongly agree** |
| 1. A comprehensive assessment should seek to increase understanding of a potential problem, and, where necessary, to describe the problem and develop a plan of action to address the problem and any needs associated with it.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. The purpose of the comprehensive assessment, and how the data may be used, should be made clear to all people involved in the assessment, including other staff members.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. A comprehensive assessment should assess multiple areas of need, including social and personal circumstances, physical health, occupational rehabilitation, and previous care and support.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. A comprehensive assessment should assess the impact that mental health problems may have on treatment planning.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. Service users should be reassessed on transfer between or out of institutions or care settings.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. Obtaining a mental health diagnosis or problem specification is central to comprehensive assessment.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. A comprehensive assessment should determine the nature, duration and severity of the presenting disorder or problem.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. A comprehensive assessment should assess any possible or established coexisting mental or physical health problems.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |

|  |
| --- |
| **Purpose of a comprehensive assessment: risk assessment and management** |
| **Statements relating to adaptations to risk assessment and management during comprehensive assessment of mental health problems in people with learning disabilities.** | **Scale** |
| **Strongly disagree** |  | **Strongly agree** |
| 1. In any comprehensive assessment the decision to undertake a risk assessment should be considered.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. Any comprehensive assessment should involve a risk assessment.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. Vulnerability to exploitation should be assessed as part of a comprehensive assessment.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. Safeguarding concerns should be assessed as part of a comprehensive assessment.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. Risk to self (self-harm, self-neglect) should be assessed as part of a comprehensive assessment.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. Risk to others (including aggression, violence and sexual offending) should be assessed as part of a comprehensive assessment.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. Risk assessment should assess the nature and severity of any behaviours, potential triggers and maintaining factors.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. Risk assessment should assess the likelihood, imminence and severity of events.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. Risk assessment should involve a systematic assessment of demographic, psychological, social and historical factors.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. Risk assessment should be informed by knowledge of the service user and their social context.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. Risk assessment should always lead to the development of a risk management plan.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. A risk management plan should identify interventions and protective factors that may reduce risk.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. The risk management plan should be communicated to relevant services or agencies.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |

|  |
| --- |
| **Purpose of a comprehensive assessment: formulation** |
| **Statements relating to formulation during comprehensive assessment of mental health problems in people with learning disabilities.** | **Scale** |
| **Strongly disagree** |  |  |  | **Strongly agree** |
| 1. A comprehensive assessment should involve a formulation of the service user’s identified problems.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. A formulation should provide a shared understanding of the nature of any problems and the factors leading to their development and maintenance.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. A formulation should provide a shared understanding of the focus and potential impact of any interventions and the barriers to delivering those interventions.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. A formulation should consider any risk factors and the impact of the social and physical environment.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |

|  |
| --- |
| **Structure of a comprehensive assessment: Staff conducting the assessment** |
| **Statements relating to the staff who should participate in a comprehensive assessment of mental health problems in people with learning disabilities.** | **Scale** |
| **Strongly disagree** |  |  |  | **Strongly agree** |
| 1. A comprehensive assessment should be conducted by a multidisciplinary team.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. A comprehensive assessment should be conducted by a clinician with specialist knowledge and understanding of mental health problems in people with a learning disability.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. A comprehensive assessment should be conducted by a clinician with specialist knowledge and understanding of mental health problems in people with a learning disability in collaboration with other professionals with relevant expertise.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. Staff involved in a comprehensive assessment should be trained and competent in using a range of assessment tools and methods relevant to people with a learning disability and a mental health problem.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. Staff involved in a comprehensive assessment should be trained and competent in using routine outcome measures relevant to people with a learning disability and a mental health problem.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. Staff conducting a comprehensive assessment should have knowledge of diagnostic classification systems.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. Staff conducting a comprehensive assessment should have knowledge of diagnostic classification systems, their limitations and specific concerns such as diagnostic overshadowing relevant to this population.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments:  |
| 1. Staff should make use of reliable pre-existing information to avoid duplicating areas of assessment that have already been undertaken.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |

|  |
| --- |
| **Structure of a comprehensive assessment: Involving service users, families and carers in the assessment** |
| **Statements relating to who else should be involved in a comprehensive assessment of mental health problems in people with learning disabilities.** | **Scale** |
| **Strongly disagree** |  |  |  | **Strongly agree** |
| 1. A comprehensive assessment should elicit service users’ views and corroborate these with families and carers.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. A comprehensive assessment should elicit service users’ views and corroborate these with professionals involved in the person’s care and other informants.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. A comprehensive assessment should consider the views of other people relevant to the care of the service user, including families, carers and other staff members, with permission and where appropriate.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. The person with a learning disability should be offered the opportunity to speak to the clinician alone, in order to elicit any concerns that they are uncomfortable sharing in front of family members or carers, including safeguarding concerns.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. A comprehensive assessment should, with the service user’s agreement, gather information from multiple data sources and informants who know the service user well.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. A comprehensive assessment should corroborate information with families and carers, if agreed by the service user.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |

|  |
| --- |
| **Structure of a comprehensive assessment: Data sources** |
| **Statements relating to data sources for a brief assessment of mental health problems in people with learning disabilities.** | **Scale** |
| **Strongly disagree** |  |  |  | **Strongly agree** |
| 1. A comprehensive assessment should aim to capture baseline data on what is typical behaviour for the person so that differences in behaviour can be evaluated.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. The impact of environmental factors on data availability and reliability should be considered in a comprehensive assessment.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. A comprehensive assessment should evaluate and integrate information from multiple sources, including structured interviews with service users and others, observations, standardised assessments, psychometric assessments and clinical records.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. A comprehensive assessment should consider whether, and how, the service user’s behaviour and functioning changes across different settings.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. A comprehensive assessment should review relevant history and past behaviour.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. Staff conducting a comprehensive assessment should be able to appraise the reliability and validity of data sources.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. Staff conducting a comprehensive assessment should use measures that have been developed in, or adapted for, people with a learning disability.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |

|  |
| --- |
| **Outcomes of a comprehensive assessment** |
| **Statements relating to outcomes from a comprehensive assessment of mental health problems in people with learning disabilities.** | **Scale** |
| **Strongly disagree** |  |  |  | **Strongly agree** |
| 1. Staff conducting a comprehensive assessment should agree with the service user appropriate outcome measures used in evaluating any care plan.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. An outcome of a comprehensive assessment should be the identification of realistic and optimistic short and medium-term goals.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. An outcome of a comprehensive assessment should be the identification of realistic and optimistic long-term goals.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. Goals for interventions should be prioritised and start with areas most likely to be amenable to change.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. When making a referral, sufficient information should be provided to allow the service to make an informed decision about how to proceed.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |

|  |
| --- |
| **Outcomes of a comprehensive assessment: The care plan** |
| **Statements relating to the care plan that should be produced from a comprehensive assessment of mental health problems in people with learning disabilities.** | **Scale** |
| **Strongly disagree** |  | **Strongly agree** |
| 1. Staff conducting the assessment should engage the service user in a collaborative discussion of their treatment options and support their participation in decision making.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. A care plan should be informed by the comprehensive assessment, the formulation that emerges from this and the service user’s goals.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. Initial care plans appropriate for the current setting should be developed as soon as possible following assessment.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. Initial care plans should be communicated in the most appropriate way to the service user and all services involved in their care in a timely manner.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. The care plan should be multidisciplinary and developed collaboratively with the service user and, if they agree, their family or carers.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. If the care plan involves a family member, partner, carer or advocate, their involvement should be used to help explain feedback from the assessment to the service user.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. The care plan should identify appropriate evidence-based interventions.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. The care plan should include a profile of the service user’s needs, including any necessary adaptations to the social or physical environment.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. The care plan should take into account the needs of families and carers.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. Risk and crisis management plans should be incorporated into the care plan.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments:  |
| 1. The care plan should identify the roles and responsibilities of all people involved in the service user’s care.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |

|  |
| --- |
| **Outcomes of a comprehensive assessment: Referral to other services** |
| **Statements relating to referrals to other services resulting from comprehensive assessment of mental health problems in people with learning disabilities.** | **Scale** |
| **Strongly disagree** |  |  |  | **Strongly agree** |
| 1. A comprehensive assessment should identify appropriate treatment and referral options in line with relevant NICE guidance.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |

|  |
| --- |
| **Outcomes of a comprehensive assessment: Monitoring of individualised and standard outcomes** |
| **Statements relating to monitoring of outcomes from a comprehensive assessment of mental health problems in people with learning disabilities.** | **Scale** |
| **Strongly disagree** |  |  |  | **Strongly agree** |
| 1. A comprehensive assessment should inform on necessary routine outcome monitoring including changes in symptoms and functioning.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. The care plan should establish a timetable to review whether goals have been met by an agreed time or point in treatment.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. Outcome measures should be selected that are designed to detect changes in the areas targeted by interventions.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. Systems should be developed for routine data sharing between other health and social care services and agencies, to reduce repetition in the assessment process.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |

* 1. Psychological interventions
		1. Round 1

**Review Q3.1: Psychological interventions to treat mental health difficulties in people with a learning disability.**

There is limited available evidence for the utility of psychological interventions to treat mental health difficulties in people with a learning disability (LD). The available evidence was presented to the Guideline Committee on 23rd July 2015 (GC 6). There was some evidence that psychological treatments may be of benefit in reducing general psychopathology in mild to moderate LD. The Guideline Committee (GC) felt that there was sufficient evidence to recommend adapted CBT for depression in people with a mild LD. However there was insufficient evidence for other psychological interventions and for other mental health difficulties.

Furthermore, there was some qualitative evidence from service users with mild to moderate LD who had accessed CBT sessions to treat mental health difficulties which indicated some issues or preferences with how the treatment was delivered. For example, some service users felt that the involvement of support workers can be valuable and help improve service-user access to sessions, some commented that the use of homework tasks sometimes felt persecutory, and many preferred ‘free floating’ rather than task-oriented sessions.

The GC agreed that a set of general principles for adaptations to psychological interventions in people with an LD would be useful. However, in the context of the lack of available evidence (and according to the agreed procedure in such situations), recommendations would need to be developed using a modified nominal group technique.

**Background on the nominal group technique**

The nominal group technique is a formal consensus method used when the scientific evidence needed to answer a clinical question is poor quality, inconsistent or non-existent.

This technique has been used in other NICE guidelines, including the guideline on behaviour that challenges in people with learning disabilities.

Highlights include:

* A method of obtaining a practical result quickly.
* Effective in obtaining consensus from a range of participants, thus generating a wide range of ideas.
* Utilises a variety of postal and face-to-face techniques to elicit a consensus view.
* Discussion structured by a facilitator.
* Individual participants (ie. GC members) record their ideas independently and privately. The ideas are then collected in turn from individuals and are fed back to the group when they are brought together for discussion, followed by a further private vote.

**Use of the nominal group technique for general principles for adapting psychological interventions**

Round 1: (by email)

* + Provide GC members with a consensus questionnaire and necessary instructions.
	+ GC members rate their agreement with the initial statements taking into account the research evidence and their clinical expertise.

***(FYI. As requested by the guideline committee, the initial statements have been circulated to expert advisers [appointed by the committee], to check content and comprehensiveness.)***

* + Ratings made using a nine-point scale (1= least agreement; 9= most agreement).
	+ Space is also provided for GC members to provide written comments on each statement (optional).

Background work conducted by review team:

* + Combine results to develop graph of distributions.
	+ Calculate median and interquartile ranges, following predefined criteria for determining consensus, e.g.
		- 100% consensus= ratings from all members fall within a single point region (1-3 disagree; 4-6, neither agree nor disagree; 7-9, agree)
	+ Rank the statements 1 to 15 based on consensus percentage.

Round 2: (at GC meeting on 22nd October)

* Provide anonymised distributions of responses to each GC member, together with each member’s response to each statement;
	+ Allows member to see the spread of views and how their own response relates.
* Typically, the statements are recirculated and the GC members would vote anonymously again (taking into consideration the anonymous comments from their fellow members). However, the challenging behaviour guideline found that they already had a very high agreement at the first stage and felt that another rating would create 100% agreement (which they felt was inappropriate). We will tailor our approach based on how high the level of agreement is at this stage:
	+ Option 1: If there is already a very high level of agreement, we will do this stage in the process in the October GC meeting. This will involve the discussion of each statement in the top half of the ranking table, together with GC members’ comments. Utilise these statements to develop recommendations.
	+ Option 2: If lower level of agreement, the statements will be recirculated for further rating and results will be discussed at the November meeting. The GC members will then use the statements to develop recommendations.

***\* Please note that similar process will be followed for other areas: questionnaires for these areas will be circulated after the October GC meeting and results will be discussed at the November GC meeting.***

MHLD CONSENSUS QUESTIONNAIRE

|  |  |
| --- | --- |
| Name: | Date: |

The following statements concern suggested adaptations to, and important considerations during the administration of, psychological interventions to treat mental health difficulties in people with a learning disability.

Statements are split into two sections, structure and content of sessions.

For each of the statements please indicate your agreement as to their appropriateness and utility by circling one number in each row. The scale works as follows:

**Number 1**: Strongly disagree with this adaptation.

**Number 5**: Neither agree nor disagree.

**Number 9**: Strongly agree that this is a useful and appropriate adaptation.

There is also room to provide comments, if you wish.

|  |
| --- |
| **Structure** |
| **Statements concerning adaptations to the structure of treatment for people with learning disabilities who have mental health difficulties.** | **Scale** |
| **Strongly disagree** |  | **Strongly agree** |
| 1. *The duration and pace of each session should be modified according to the capacity of the individual to engage. For example, sessions should be shorter in duration, slower paced and more frequent than for people without a learning disability.*
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments:  |
| 1. *The person’s ability to correctly identify and label their emotions, and identify situations or thoughts which may make them feel a certain way, should be evaluated prior to commencement of therapy.*
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. *A course of treatment may need to be longer, with sessions closer together, than for people without a learning disability to allow more time to establish a therapeutic alliance, for learning, and for consolidation of concepts.*
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. *Structure sessions using an agenda or visual timetable which sets out what the session aims to achieve, with the goals of the intervention clearly indicated.*
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. *Use a written or visual agenda depending on the capabilities of the individual.*
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. *The choice of intervention and introduction of subsequent adaptations should be informed by the person’s strengths and weaknesses, employing areas of relative strength, such as verbal abilities in people with William’s Syndrome, as much as possible.*
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. *The importance of routine should be considered when establishing a treatment plan and scheduling appointments. For example, scheduling at the same time and in the same place as often as possible and that sessions follow a consistent format.*
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. *Ensure that the individual’s needs, including physical disabilities, distractibility and sensitivity to noise, are considered carefully when choosing a location for therapy sessions.*
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |

|  |
| --- |
| **Structure** |
| 1. *Deliver interventions face-to-face.*
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| **Content** |
| **Statements concerning adaptations to the content of psychological intervention sessions for people with learning disabilities who have mental health difficulties.** | **Scale** |
| **Strongly disagree** |  |  |  | **Strongly agree** |
| 1. *All aspects of the intervention, including the setting of goals and evaluation of progress, should be as collaborative as possible.*
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. *Consider reducing the reliance upon written materials and activities, such as workbooks and diaries. For example, consider using materials such as pictures and simple diagrams.*
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. *Continue to use written materials and activities such as homework diaries and workbooks, but provide support to the person to use these.*
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. *Use concrete examples, visual methods and practical demonstrations to explain concepts.*
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. *If the individual has a specific area of interest it may be helpful to try and use this to improve understanding and engagement with sessions.*
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. *It is important to adapt to the individual’s level of understanding.*
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. *If thought to be helpful, undertake some initial work to help the person to identify and label their own emotions.*
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. *Identify and use the terms clients themselves use to describe their emotions.*
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. *Provide opportunities to practise and generalise any new skills developed through treatment.*
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. *Ensure systems are in place to support practice between sessions.*
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. *Consider whether the individual has difficulty generalising information across different settings such as home, school, and therapy. If so, provide support to achieve this.*
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. *Employ a range of aids to facilitate communication and understanding including: clear, straight-forward language, role plays, visual and practical aids and modelling.*
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. *Consider involving a family member or carer to facilitate engagement.*
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. *Consider involving a family member or carer to assist with implementation.*
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. *Support individuals to identify and reflect on change and progress after treatment using different methods such as a thermometer or numerical scale.*
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |

* + 1. Round 2 (Mild to moderate)

MHLD CONSENSUS QUESTIONNAIRE

|  |  |
| --- | --- |
| Name: | Date: |

**Adaptations to psychological interventions for people with mild to moderate LD**

The following statements concern suggested adaptations to, and important considerations during the administration of, psychological interventions to treat mental health difficulties in people with a **mild or moderate** learning disability.

Recommendations about adaptations to psychological interventions will be informed from the nominal group statements in which there is at least 80% agreement. These ‘adaptation’ recommendations will follow initial recommendations about which psychological interventions should be considered in those with mild to moderate LD and a mental health problem which will be based on the evidence presented to the committee (draft recommendations will be discussed with the group).

Statements are split into several sections; General (p. 2), Setting (p. 2), Structure (p. 2-3), Content (p. 4-6) and Involving others (p. 7). Please ensure you have checked both sides of each sheet of paper, so that no items are missed.

For each of the statements please indicate your agreement as to their appropriateness and utility by circling one number in each row. The scale works as follows:

**Number 1**: Strongly disagree with this adaptation.

**Number 5**: Neither agree nor disagree.

**Number 9**: Strongly agree that this is a useful and appropriate adaptation.

There is also room to provide comments, if you wish.

|  |
| --- |
| **General** |
|  | **Scale** |
| **Strongly disagree** |  | **Strongly agree** |
| 1. People with a learning disability may have a broad range of sensory, physical, cognitive and communication difficulties; any adaptations to psychological treatments should be informed by careful assessment of the person and tailored to their needs.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments:  |
| **Setting** |
| **Statements relating to adaptations to the setting in which psychological interventions may be provided for people with learning disabilities and mental health problems.**  | **Scale** |
| **Strongly disagree** |  | **Strongly agree** |
| 1. Ensure that the chosen setting provides sufficient privacy (such as when offering treatment on an outreach basis).
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. When choosing a location for therapy sessions ensure that the person’s needs, for example neurological or physical health problems or sensory sensitivities, are taken into account.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. The mode of delivery of an intervention, for example face-to-face or online, should be decided based on the person’s needs rather than the preference of the service.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| **Structure** |
| **Statements relating to adaptations to the structure of psychological interventions provided to people with learning disabilities and mental health problems.** | **Scale** |
| **Strongly disagree** |  | **Strongly agree** |
| 1. The choice of intervention and introduction of adaptations should be informed by the person’s strengths and weaknesses identified during assessment, drawing on areas of relative strength as much as possible.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. When establishing a treatment plan and scheduling appointments, whether routine is important to, or would be helpful for, the person should be taken into account.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. For some people with a learning disability, for instance those with autistic traits or memory impairments, scheduling therapy sessions at the same time of day/week and in the same place, and ensuring that sessions follow a consistent format, can be beneficial.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. The duration of each therapy session should be modified according to the person’s needs.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. Therapy sessions may need to be shorter or longer than the standard clinical hour or breaks may need to be provided.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. The pace of each therapy session should be modified according to the person’s needs.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. Therapy sessions may need to be slower paced and/or include more repetition of key concepts.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. Thought should be given to the frequency of therapy sessions, taking into account clinical need and the frequency of the person’s other appointments.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. In order to guide individualisation of the intervention, the person’s ability to identify their emotions, and thoughts or situations which make them feel a certain way, should be evaluated before starting treatment.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. A course of treatment may need to be longer than for people without a learning disability to allow more time for learning and consolidation of concepts.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. Consider providing reminders to assist in the completion of homework tasks.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |

|  |
| --- |
| **Content** |
| **Statements concerning adaptations to the content of psychological intervention sessions for people with learning disabilities who have mental health difficulties.** | **Scale** |
| **Strongly disagree** |  |  |  | **Strongly agree** |
| 1. Maintain an awareness of the potential impact of the person’s experiences of stigma and prejudice on engagement with therapy.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
|  |
| 1. Clinicians should be careful to communicate with the person with a learning disability and mental health problem directly, rather than talking about, or over them.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
|  |
| 1. Psychological interventions should be adapted to the person’s level of understanding.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
|  |
| 1. If indicated by assessment, initial work may be undertaken to help the person to identify and label their own emotions.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
|  |
| 1. The terms that the person uses to describe their emotions should be used during therapy sessions.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
|  |
| 1. All aspects of the intervention, including the setting of goals and evaluation of progress, should be developed collaboratively with the person.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
|  |
| 1. Agreed goals for the intervention should be clear and concrete.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
|  |
| 1. The agenda for the session should be communicated in the way most suited to the person, for example in a written format, visually, orally or a combination of these.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
|  |
| 1. A range of aids to facilitate communication and understanding should be used including role play, visual and practical aids and modelling*.*
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
|  |
| 1. Explanations should be provided in clear, straightforward language; complicated sentences should be avoided.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
|  |
| 1. Abstract visual stimuli, such as symbols, may require explanation as to their meaning and purpose.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
|  |
| 1. Repeating key messages can help the person remember them.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
|  |
| 1. It may be helpful to regularly summarise and review the material covered.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
|  |
| 1. It may be helpful to check understanding at regular intervals and clarify areas of confusion.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
|  |
| 1. Depending on the person’s needs and preferences, reducing reliance on written materials and activities (such as workbooks and diaries) and using materials such as pictures and diagrams, should be considered.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. If written materials and activities such as (workbooks and diaries) are used, it should be assessed whether the person will require any support to use these.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. The use of abstract examples should be avoided as much as possible. Concrete examples, visual methods and practical demonstrations should be used to explain concepts.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. If the person has a specific area of interest, consider incorporating this into therapy sessions to improve engagement and understanding of concepts. It should be borne in mind that this may not be a helpful approach with people who are very perseverative or have a rehearsed script around a topic.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. In-session opportunities to practise and generalise new skills, depending on the person’s needs, should be considered.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. Thought should be given to the best way of supporting people to identify and reflect upon change both during and at the end of the intervention.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. The choice of progress and outcome measure should be based on the person’s needs and understanding, and could include tools such as face scales, thermometers to depict anger or distress, or numerical scales.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |

|  |
| --- |
| **Involving others** |
| **Statements concerning involving others in psychological intervention sessions for people with learning disabilities who have mental health difficulties.** | **Scale** |
| **Strongly disagree** |  |  |  | **Strongly agree** |
| 1. If appropriate, a family member or carer may be involved in the therapeutic process to facilitate engagement.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. If appropriate, involving a family member of carer may help to assist with implementation of the intervention, including in the person’s everyday life.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. It should be discussed with the person whether they require any support to practice new skills between sessions. If support is required, liaise with relevant individuals or services to ensure that this is put in place.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. If appropriate, a family member or carer may help maintain change after the therapy has finished by supporting the individual to continue using strategies learned.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. Care needs to be taken to avoid inviting family or carer members to take part in the therapy if they are in conflict with the individual or involved in the individual’s distress.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. When considering whether to involve the family or carer member in therapy the individual with a learning disability and a mental health problem should be asked for their views.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. If the person is experiencing difficulties generalising information learnt within sessions to other settings, discuss with the person how to address this and liaise with relevant individuals or services to implement necessary support.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |

* + 1. Round 2 (Severe to Profound)

MHLD CONSENSUS QUESTIONNAIRE

|  |  |
| --- | --- |
| Name: | Date: |

**Interventions or adaptations to interventions for people with severe to profound LD**

Apart from some very low-quality evidence on the use of relaxation therapy for anxiety, the literature review did not find evidence on interventions for people with **severe to profound learning disabilities** with mental health problems that was of sufficient methodological quality, as outlined in the review protocols, to include in the review. Therefore statements regarding interventions or adaptations to interventions have been developed to be assessed by the group through the nominal group technique.

Recommendations will be informed from the nominal group statements in which there is at least 80% agreement. Draft recommendations will be discussed with the group.

Please ensure you have checked both sides of each sheet of paper, so that no items are missed.

For each of the statements please indicate your agreement as to their appropriateness and utility by circling one number in each row. The scale works as follows:

**Number 1**: Strongly disagree with this adaptation.

**Number 5**: Neither agree nor disagree.

**Number 9**: Strongly agree that this is a useful and appropriate adaptation.

There is also room to provide comments, if you wish.

|  |
| --- |
| **Interventions or adaptations to interventions for people with severe to profound learning disabilities** |
| **Statements relating to interventions or adaptations to interventions for people with severe to profound learning disabilities and a mental health problems.** | **Scale** |
| **Strongly disagree** |  |  |  | **Strongly agree** |
| 1. For people with severe or profound learning disabilities, it may be particularly useful to help to manage the person’s environment to reduce stressors or to help them to manage change.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. For people with severe or profound learning disabilities with mental health problems, techniques that involve demonstration (such as modelling) are likely to be more beneficial at treating the mental health problem than techniques that involve verbal explanations.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. For people with severe or profound learning disabilities with mental health problems, psychological or psychosocial interventions should include clear, structured activities and provide support to the person to engage with the activities.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. For people with severe or profound learning disabilities with phobias and anxiety problems, graded exposure may be useful in supporting the person to deal with these problems.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. Staff working with people with severe or profound learning disabilities with mental health problems should work with the family members or carers of the person to ensure that their input is consistent and sensitive to the individual.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |

* 1. Pharmacological interventions
		1. Round 1

MHLD CONSENSUS QUESTIONNAIRE

|  |  |
| --- | --- |
| Name: | Date: |

**Adaptations to pharmacological interventions for people with an LD and mental health problems**

The following statements concern suggested adaptations to pharmacological interventions to treat mental health difficulties in people with a learning disability.

Recommendations about adaptations to pharmacological interventions will be informed from the nominal group statements in which there is at least 80% agreement. These ‘adaptation’ recommendations will follow initial recommendations about which pharmacological interventions should be considered in those with an LD and a mental health problem which will be based on the evidence presented to the committee (draft recommendations have been discussed with the group).

For each of the statements please indicate your agreement as to their appropriateness and utility by circling one number in each row. The scale works as follows:

**Number 1**: Strongly disagree with this adaptation.

**Number 5**: Neither agree nor disagree.

**Number 9**: Strongly agree that this is a useful and appropriate adaptation.

There is also room to provide comments, if you wish.

|  |
| --- |
| **Treatment and Management** |
| **Statements concerning adaptations to pharmacological interventions to treat and manage mental health problems in people with learning disabilities.** | **Scale** |
| **Strongly disagree** |  |  |  | **Strongly agree** |
| 1. Only learning disabilities specialists should start drug treatment for a mental health problem in people with a learning disability.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. Before prescribing a drug to treat a mental health problem in people with a learning disability, there needs to be careful consideration of a number of things when obtaining consent including the mode of communication.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. Before prescribing a drug to treat a mental health problem in people with a learning disability, there needs to be careful consideration of a number of things when obtaining consent including the environment where the information is provided.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. Before prescribing a drug to treat a mental health problem in people with a learning disability, there needs to be careful consideration of a number of things when obtaining consent including the person’s familiarity with whoever provides the information.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. Before prescribing a drug to treat a mental health problem in people with a learning disability, there needs to be careful consideration of a number of things when obtaining consent including the pace the information is provided.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. Before prescribing a drug to treat a mental health problem in people with a learning disability, there needs to be careful consideration of a number of things when obtaining consent including the person’s capacity to consent.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. The potential for people with a learning disability and a mental health problem to react to psychotropic medication atypically should be taken into account.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. Additional risk factors due to underlying syndromes (such as cardiovascular risk factors, difficulties with weight management, increased susceptibility to metabolic syndromes) should be borne in mind before prescribing a drug to treat a mental health problem in people with a learning disability.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. Before prescribing a drug to treat a mental health problem in people with a learning disability, the difficulty of taking blood samples from some people with a learning disability should be borne in mind.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. Before prescribing a drug to treat a mental health problem in people with a learning disability, likely compliance issues, should be borne in mind.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. It may be helpful to support and monitor people with mild learning disabilities who are taking medication for mental health problems to improve compliance with drug regimens (such as through blood testing).
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. The potential difficulties for people with a learning disability and a mental health problem in tolerating or communicating any side effects should be borne in mind.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. When prescribing a drug to treat a mental health problem in people with a learning disability, polypharmacy should be avoided.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. To avoid polypharmacy, regular comprehensive medication review is necessary.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. When prescribing a drug to treat a mental health problem in people with a learning disability, any drugs that the person is taking for other conditions (such as epilepsy) should be taken into consideration.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. Cardiovascular investigations should be undertaken before prescribing a drug to treat a mental health problem because of an increased risk of stroke in some people with a learning disability.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. ‘Easy read’ written or pictorial instructions can be helpful to increase compliance with drug treatment in people with a learning disability.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. When prescribing a drug to treat a mental health problem in people with a learning disability, prescribing clinicians should start with a low dose.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. When determining the initial dose, prescribing clinicians should balance the need to ensure a low dose to monitor for side effects while avoiding sub-therapeutic doses that may not treat the mental health problem effectively.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. If the person with a learning disability is physically healthy, the mean therapeutic dose recommended for use in the non-learning disability population may be appropriate.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. The dose of a drug to treat a mental health problem in people with a learning disability should be increased very gradually.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. Particular care needs to be taken when discontinuing a drug in people with a learning disability because symptoms may be exacerbated such as with selective serotonin reuptake inhibitors (SSRIs) for anxiety.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. Particular vigilance for side effects should be exercised when starting or changing a drug to treat a mental health problem in a person with a learning disability.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. Before prescribing a drug to treat a mental health problem in people with a learning disability, clinicians should ensure that they liaise with any other involved specialists (such as neurologists for epilepsy care) to discuss existing drug regimens and possible interactions.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. Prescribing clinicians should liaise with other involved specialists (such as neurologists for epilepsy care) regarding the person’s drug regimen.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. A drug used to treat a mental health problem in people with a learning disability should be reviewed for effectiveness and side effects after 3 to 4 weeks.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. A drug used to treat a mental health problem in people with a learning disability should be reviewed for effectiveness and side effects after 6 weeks.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. Use of in people with a learning disability and a mental health problem should ideally not be used in the long-term.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. Psychotropic medication for behavioural and cognitive symptoms in dementia should only be considered if other approaches have been ineffective and risk from symptoms is high.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. Drug treatment for a mental health problem in people with a learning disability should be reviewed by learning disabilities specialists, unless there are locally agreed protocols for shared care.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |

* 1. Other interventions
		1. Social and environmental interventions
			1. Round 1

MHLD CONSENSUS QUESTIONNAIRE

|  |  |
| --- | --- |
| Name:  | Date: |

The literature review did not find evidence on the use of social and physical environmental interventions for either the prevention (RQ2.2) or treatment/management (Q3.2) of mental health problems that was of sufficient methodological quality, as outlined in the review protocols, to include in the review.

It will be possible to cross-refer to existing guidelines that have recommendations in these areas. However, statements regarding adaptations to social and physical environment for people with LD have been developed to be assessed by the group through the nominal group technique.

Statements are split into two sections; Prevention of mental health problems in people with LD (p. 2) and Treatment or management of mental health problems in people with LD (p. 3). Please ensure you have checked both sides of each sheet of paper, so that no items are missed.

For each of the statements please indicate your agreement as to their appropriateness and utility by circling one number in each row. The scale works as follows:

**Number 1**: Strongly disagree with this adaptation.

**Number 5**: Neither agree nor disagree.

**Number 9**: Strongly agree that this is a useful and appropriate adaptation.

There is also room to provide comments, if you wish.

|  |
| --- |
| **Prevention** |
| **Statements relating to social and physical environmental adaptations that may help prevent the development of mental health problems in people with learning disabilities.** | **Scale** |
| **Strongly disagree** |  | **Strongly agree** |
| 1. Social relationships may help prevent the development of mental health problems in people with a learning disability.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. Support to develop and maintain fulfilling social relationships, including intimate relationships, may help prevent the development of mental health problems in people with a learning disability.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. Additional support for people with a learning disability to develop and maintain fulfilling social relationships may be provided by families and carers, or through formal educational programs.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. People with a learning disability should be offered social opportunities that will allow them to develop meaningful social relationships.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. People with a learning disability should not be subject to frequent changes of environment.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. When changes to the care setting of a person with a learning disability are required, the details should be explained and consent should be obtained.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments:  |
| 1. When changes to the environment of people with a learning disability are necessary, the change should be planned in advance.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments:  |
| 1. Where possible, people with a learning disability and their families and carers should be provided with the support necessary to allow them to live at home, and as independently as possible.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments:  |

|  |
| --- |
| **Content** |
| **Statements relating to social and physical environmental adaptations that may help in the treatment or management of mental health problems in people with learning disabilities.** | **Scale** |
| **Strongly disagree** |  |  |  | **Strongly agree** |
| 1. Social relationships can help people with a learning disability manage mental health problems.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. People with a learning disability and mental health problem may require additional support to develop and maintain fulfilling social relationships, including intimate relationships.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. People with a learning disability and a mental health problem should be supported to develop fulfilling social relationships, including intimate relationships.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. Additional support for people with a learning disability and mental health problem to develop and maintain fulfilling social relationships can be provided informally by families and carers or through education programmes.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. People with a learning disability and mental health problem should be offered social opportunities that will allow them to develop meaningful social relationships. People with a learning disability and a mental health problem should not be subject to frequent changes of care setting.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. When changes to the care setting of people with a learning disability and a mental health problem are necessary, the details should be clearly explained and consent should be obtained.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments:  |
| 1. When changes to the environment of people with a learning disability and a mental health problem are necessary, the change should be planned in advance.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. Depending upon their individual needs, people with a learning disability and a mental health problem should be able to live at home with varying degrees of independence, as needed; removal to institutionalised care should be the exception rather than the rule.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |

* + - 1. Round 2

MHLD CONSENSUS QUESTIONNAIRE

|  |  |
| --- | --- |
| Name: | Date: |

The literature review did not find evidence on the use of social and physical environmental interventions for either the prevention (RQ2.2) or treatment/management (Q3.2) of mental health problems that was of sufficient methodological quality, as outlined in the review protocols, to include in the review.

It will be possible to cross-refer to existing guidelines that have recommendations in these areas. However, statements regarding adaptations to social and physical environment for people with LD have been developed to be assessed by the group through the nominal group technique.

Please ensure you have checked both sides of each sheet of paper, so that no items are missed.

For each of the statements please indicate your agreement as to their appropriateness and utility by circling one number in each row. The scale works as follows:

**Number 1**: Strongly disagree with this adaptation.

**Number 5**: Neither agree nor disagree.

**Number 9**: Strongly agree that this is a useful and appropriate adaptation.

There is also room to provide comments, if you wish.

|  |  |
| --- | --- |
|  | **Scale** |
| **Strongly disagree** |  | **Strongly agree** |
| 1. People with a learning disability and mental health problem should be assisted to live independently if they wish to do so.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. People with a learning disability and mental health problem should be assisted to live within their family home.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. If people with a learning disability and mental health problem are unable to live either independently or with their family they should be offered a place that is close to important members of their social and support network.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. The person with a learning disability and mental health problem should be empowered to make a decision about living environment that is right for them and their needs.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. Provide a positive educational environment for a person with a learning disability and mental health problem.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. Provide consistent physical healthcare for a person with a learning disability and mental health problem.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. Where a person with a learning disability and mental health problem is cared for by their family within the family home, alternatives should be considered as the parents approach later life.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. Care should be taken when arranging foster or other care placements for children for children and young people with a learning disability and mental health problem, to minimise the risk of placement breakdown.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. Opportunities to participate in a range of social activities of interest to the individual should be offered.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. Opportunities to participate in community activities of interest to the individual should be offered.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. When mental health difficulties emerge or worsen, consider the possibility that environmental or social factors have contributed to these.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. When mental health difficulties emerge or worsen, consider the possibility that changes to social relationships may alleviate these.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. In people with a severe or profound learning disability, consider that the nature and quality of the physical environment can have a significant positive or negative impact upon their health and wellbeing.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. In people with a severe or profound learning disability and mental health problems careful consideration should be given to the physical environment.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |

* + 1. Occupational interventions
			1. Round 1

MHLD CONSENSUS QUESTIONNAIRE

|  |  |
| --- | --- |
| Name: | Date: |

The literature review did not find evidence on the use of occupational interventions for either the prevention (RQ2.8) or treatment/management (R3.8) of mental health problems that was of sufficient methodological quality, as outlined in the review protocols, to include in the review.

It will be possible to cross-refer to existing guidelines that have recommendations in these areas. However, statements regarding occupational interventions for people with LD have been developed to be assessed by the group through the nominal group technique.

Statements are split into several sections; General (p. 2), Prevention (p. 2-3) and Treatment (p. 4). Please ensure you have checked both sides of each sheet of paper, so that no items are missed.

For each of the statements please indicate your agreement as to their appropriateness and utility by circling one number in each row. The scale works as follows:

**Number 1**: Strongly disagree with this adaptation.

**Number 5**: Neither agree nor disagree.

**Number 9**: Strongly agree that this is a useful and appropriate adaptation.

There is also room to provide comments, if you wish.

|  |
| --- |
| **General** |
| **General statements** | **Scale** |
| **Strongly disagree** |  | **Strongly agree** |
| 1. People with a learning disability may have a broad range of sensory, physical, cognitive and communication difficulties; the use of occupational interventions should be informed by understanding of the person and tailored to their needs.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments:  |
| **Prevention** |
| **Statements relating to occupational interventions that may be provided for people with learning disabilities to help prevent mental health problems.**  | **Scale** |
| **Strongly disagree** |  | **Strongly agree** |
| 1. Adults with a learning disability should be actively encouraged and supported (for example, by their support worker) to find and participate in meaningful work, either paid or voluntary, if it is possible for them to do so.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. Adults with a learning disability who are capable of participating in meaningful work should be provided with opportunities to do so.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. Young people with a learning disability may benefit from support to identify personal strengths, potential occupations of interest and to develop work skills at special educational needs colleges.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. Services should provide information and guidance to people with a learning disability regarding tasks that are typically required to find employment (either paid or voluntary).
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. People with a learning disability should be offered practical support with specific tasks typically required to find employment (substantive or voluntary) with writing a CV, completing application forms, preparing for interviews and completing any pre-employment checks, as necessary.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. Services should assist people with a learning disability and potential employers in identifying areas of potential difficulty during employment, and how best to prevent these.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. Support workers should assist people with a learning disability in addressing any work difficulties in order to help them remain engaged in meaningful activity.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |

|  |
| --- |
| **Treatment** |
| **Statements concerning occupational interventions to treat or manage mental health problems in people with learning disabilities.** | **Scale** |
| **Strongly disagree** |  |  |  | **Strongly agree** |
| 1. Adults with a learning disability and a mental health problem should be actively encouraged and supported (for example, by their support worker) to find and participate in meaningful work, either paid or voluntary, if it is possible for them to do so.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. Adults with a learning disability and a mental health problem who are capable of participating in meaningful work should be provided with opportunities to do so.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. Young people with a learning disability and a mental health problem may benefit from support to identify personal strengths, potential occupations of interest and to develop work skills at special educational needs colleges.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. Services should provide information and guidance to people with a learning disability and a mental health problem regarding tasks that are typically required to find employment (either paid or voluntary).
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. People with a learning disability and a mental health problem should be offered practical support with specific tasks typically required to find employment (substantive or voluntary) with writing a CV, completing application forms, preparing for interviews and completing any pre-employment checks, as necessary.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. Services should assist people with a learning disability and a mental health problem and potential employers in identifying areas of potential difficulty during employment, and how best to prevent these.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. Support workers should assist people with a learning disability and mental health problem in addressing any work difficulties in order to help them remain engaged in meaningful activity.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |

* 1. Organisation and service delivery
		1. Round 1

MHLD CONSENSUS QUESTIONNAIRE

|  |  |
| --- | --- |
| Name: | Date: |

**Organisation and delivery of support**

The literature review did not find sufficient evidence on organisation and service delivery of support for people with a learning disability and mental health problem to inform recommendations in this area. Therefore statements regarding these areas have been developed to be assessed by the group through the nominal group technique.

Statements are split into 6 sections:

1. Structures, training and supervision to support practitioners in the effective delivery of interventions (RQ4.6) (p. 2-3)
2. Improving accessibility of services (RQ4.1) (p. 4)
3. Models or support for transition between services (RQ4.2) (p. 4-6)
4. Coordination and communication between key persons and services in the life of a person with LD and MH problems (RQ4.3) (p. 6-7)
5. Engaging the family and staff/advocate of people with LD in the design, implementation and monitoring of interventions for that person’s mental health problems (RQ4.4) (p. 7-8)
6. Engaging and empowering service users with LD in the design, implementation and monitoring of interventions for that person’s mental health problems (RQ4.5) (p. 9-10)

*(Please note that these have been categorised that are structured under the relevant review questions but some statements may fit under more than one category. For example, some statements about coordination between key persons and services [RQ4.3] might also be considered under structures to support practitioners in the effective delivery of interventions [RQ4.6]. The recommendations in the guideline may be organised in a slightly different way.)*

Please ensure you have checked both sides of each sheet of paper, so that no items are missed.

For each of the statements please indicate your agreement as to their appropriateness and utility by circling one number in each row. The scale works as follows:

**Number 1**: Strongly disagree with this adaptation.

**Number 5**: Neither agree nor disagree.

**Number 9**: Strongly agree that this is a useful and appropriate adaptation.

There is also room to provide comments, if you wish.

|  |
| --- |
| **Structures, training and supervision to support practitioners in the effective delivery of interventions** |
| **Statements relating to structures, training and supervision to support practitioners in the effective delivery of interventions.** | **Scale** |
| **Strongly disagree** |  |  |  | **Strongly agree** |
| 1. Services for people with a learning disability and a mental health problem should be co-located, if possible, in order to facilitate co-working and joined-up service provision.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. To prevent people with a learning disability and a mental health problem from falling ‘between the gaps’ of different services, care should generally be provided within mainstream mental health services with staff who have appropriate specialist training in working with people with learning disabilities.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. Where people with a learning disability and a mental health problem are treated in mainstream settings (such as by a crisis or home response team), care coordinators should ensure that these services are fully informed of the nature of the person’s disability and the impact on the mental health problem.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. General mental health service who provide crisis care to people with a learning disability and mental health problem should ensure that they are fully informed about the nature of the learning disability.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. Specific dedicated beds should be provided in a general mental health service for people with a learning disability and a mental health problem who require an acute admission.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. Inpatient services with dedicated beds for people with a learning disability and mental health problem should have staff with specialists training in learning disability.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. General mental health services who provide out- or day-patient care for people with a learning disability and a mental health problem should employ staff who are competent to treat and aware of the interaction between the learning disability and mental health problems.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. To improve outcomes in people with a learning disability and a severe mental health problem intensive support at home and in community settings, with provision for more frequent contact with services, could be considered.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. If care is not provided by a practitioner with accredited specialist skills in work with people with a learning disability and a mental health problem, supervision must be provided by a more senior member of staff who has these skills.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. Guidance and supervision should be sought by any staff member working with an individual with a learning disability and a mental health problem from a colleague with appropriate accredited specialist skills.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. All staff who will work with people with a learning disability and a mental health problem should receive training in the needs of people with a learning disability, including issues relating to safeguarding and communication challenges, and the potential different presentations of mental health problems in these people.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. Staff who work with people with a learning disability and a mental health problem on a regular basis should receive training in the needs of people with a learning disability, including issues relating to safeguarding and communication challenges, and the potential different presentations of mental health problems in these people.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. Specialist LD services should have the capacity to offer a broad range of psychological interventions for common and severe mental disorders.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. Generic psychological treatment services (for example, IAPT) should have the competence to be able to delivery treatment to people with LD.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. Generic MH services should have the competence to be able to delivery treatment to people with LD.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |

|  |
| --- |
| **Improving accessibility of services** |
| **Statements relating to general principles for improving accessibility of services for people with a learning disability and a mental health problem.** | **Scale** |
| **Strongly disagree** |  | **Strongly agree** |
| 1. Services for people with a learning disability and a mental health problem should be delivered flexibly, taking into account the person’s needs (including financial considerations, mobility needs or any anxieties about travel).
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. Services for people with learning disabilities and mental health problems should be delivered flexibly (including provision of care outside of the care environment) where possible.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. Services for people with a learning disability and a mental health problem should be accessible to people from different cultural backgrounds.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. When a person with a learning disability and a mental health problem is having difficulties accessing services, consider if communication difficulties may be a contributing factor.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. For people with a learning disability and a mental health problem service-user preference for a worker of a particular gender, or ethnic or cultural background, should be accommodated where possible.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |

|  |
| --- |
| **Models or support for transition between services**  |
| **Statements relating to general principles for improving transition between services for people with a learning disability and a mental health problem.** | **Scale** |
| **Strongly disagree** |  |  |  | **Strongly agree** |
| 1. Transitions for people with a learning disability and a mental health problem should be planned in advance.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. The person with a learning disability and a mental health problem and their families and carers should be involved in the planning of transitions.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. All effort should be made to ensure the person with a learning disability and a mental health problem feels adequately supported during transitions.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. When a person with a learning disability and a mental health problem is transitioning between services, all effort should be made to ensure a smooth transition of care.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. For people with a learning disability and a mental health problem, a key individual should be identified to facilitate a smooth transition between services.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. For people with a learning disability and a mental health problem consideration should be given to any special requirements that may assist with a smooth transition between services (such as difficulties with changes to routine or anxiety about meeting new people).
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. A joint meeting should be held during the transition period with the person with a learning disability and a mental health problem, their families and carers and staff from both the outgoing and incoming services.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. Children and young people with a learning disability and a mental health problem who are within the care system should receive additional support when transitioning between settings.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. People with a learning disability and a mental health problem who are admitted to hospital because of neurological or physical health problems should receive additional support during admission or discharge.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. For people with a learning disability and a mental health problem, a referral needs to be accepted by the organisation accepting care before discharge from the referring organisation.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. When a person’s care is being transferred to another service or organisation, the referring or discharging organisations should ensure that information related to the person with a learning disability and a mental health problem and their families and carers is provided securely and in a timely manner to the organisation accepting care.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. When a person’s care is being transferred to another service or organisation, the referring or discharging organisation should ensure that information relating to any safeguarding concerns for the person with a learning disability and a mental health problem is shared with all relevant services.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. It is the responsibility of the organisation accepting care to ensure that they have received the person’s records, including any safeguarding concerns.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. In educational settings, children and adolescent mental health services staff should provide advice and facilitate transitions for people with learning disabilities and mental health problems.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |

|  |
| --- |
| **Coordination and communication between key persons and services in the life of a person with LD and MH problems**  |
| **Statements relating to general principles for coordination and communication between key persons and services in the life of a person with LD and MH problems.** | **Scale** |
| **Strongly disagree** |  |  |  | **Strongly agree** |
| 1. All involved agencies should ensure that they communicate information clearly, both between services and with the person with a learning disability and a mental health problem and any key people involved (such as family members or carers).
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. A key worker should be allocated who co-ordinates all aspects of care for people with a learning disability and a mental health problem.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. A key worker should be allocated to facilitate clear communication between the person with a learning disability and mental health problem, their family and carers, and involved services.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. For people with a learning disability and a mental health problem, a proactive approach should be taken to the sharing of information with key people and services, in line with local procedures and with the permission of the person with a learning disability and a mental health problem.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. It is important that staff familiarise themselves with the role of each key person or service in **the** life of the person with a learning disability and a mental health problem.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. It is important that staff familiarise themselves with the working practices of each key person or service in the life of the person with a learning disability and a mental health problem.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. It is important for each key person and service to clarify their role and responsibility regarding the care of the person with a learning disability and a mental health problem.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. Communications between key persons in the life of a person with a learning disability and a mental health problem should be timely and in an agreed format.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. For people with a learning disability and a mental health problem, clarity of coordination and communication is particularly crucial regarding safeguarding concerns and risk management.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |

|  |
| --- |
| **Engaging the family and staff/advocate of people with LD in the design, implementation and monitoring of interventions for that person’s mental health problems** |
| **Statements relating to engaging the family and staff/advocate of people with learning disabilities in the design, implementation and monitoring of interventions for that person’s mental health problems.** | **Scale** |
| **Strongly disagree** |  |  |  | **Strongly agree** |
| 1. It may be helpful to consult family members, carers and staff/advocates of people with a learning disability and a mental health problem, if possible, to inform the design of interventions to treat the person’s mental health problems.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. When designing an intervention for a person with a learning disability and a mental health problem, input from and knowledge of family members, carers and staff/advocates should be sought, with the person’s permission if possible.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. When implementing interventions for people with a learning disability and a mental health problem, it may be helpful to consider offering consultation to family members, carers and staff/advocates.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. Family members, carers and staff/advocates of people with a learning disability and a mental health problem should be encouraged to be actively involved in the implementation of intervention plans to treat the person’s mental health problems.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. Family members, carers and staff/advocates of people with a learning disability and a mental health problem should be encouraged to be actively involved in the implementation of intervention plans to treat the persons’ mental health problems, including attendance at sessions so that they feel able to adopt a co-therapist role, if this is felt to be appropriate.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. When considering the progress and acceptability of interventions for people with a learning disability and a mental health problem, the opinions of family members, carers and staff/advocates should be sought via attendance at sessions, if possible (and if this is not feasible, via telephone).
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. When considering the progress and acceptability of interventions for people with a learning disability and a mental health problem, the opinions of family members, carers and staff/advocates should be sought using standardised outcome measurement tools via post.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. Family members or carers of people with a learning disability and a mental health problem should be provided with information about support and interventions in an appropriate language and format, including NICE’s ‘Information for the Public’.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |

|  |
| --- |
| **Engaging and empowering service users with LD in the design, implementation and monitoring of interventions for that person’s mental health problems** |
| **Statements relating to engaging and empowering service users with LD in the design, implementation and monitoring of interventions for that person’s mental health problems.** | **Scale** |
| **Strongly disagree** |  |  |  | **Strongly agree** |
| 1. Before delivering interventions to people with a learning disability and mental health problem allow sufficient preparation time for service users and their carers about what to expect from the treatment by providing them with information (in an ‘easy read’ format, using lay terms) at the time of arranging the treatment.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. Before delivering interventions to people with a learning disability and mental health problem allow sufficient preparation time for service users and their carers about what to expect from the treatment by providing them with information (in ‘easy read’ format, using lay terms) at some point in advance of the treatment.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. For people with a learning disability and a mental health problem who are undergoing an intervention, their understanding of the purpose, plan and content of the intervention should be checked at the start and then regularly throughout.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. Staff members should allocate time to thoroughly explain to the person with a learning disability and a mental health problem any outcome measures that are used to monitor progress during an intervention.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. Staff members should offer support to people with a learning disability and a mental health problem to complete any outcome measures used to monitor progress during an intervention.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. To ensure that the service user feels able to engage as fully as possible, communication needs and degree of understanding should be held in mind at all stages of the intervention.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. Families and carers should be involved in assisting with the implementation of the intervention, if possible and if agreed with the person with a learning disability and a mental health problem.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. If possible, the views of families and carers should be elicited to monitor the implementation of interventions for people with a learning disability and a mental health problem and progress towards goals.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |

* + 1. Round 2

MHLD CONSENSUS QUESTIONNAIRE

|  |  |
| --- | --- |
| Name: | Date: |

**Organisation and delivery of support**

The literature review did not find sufficient evidence on organisation and service delivery of support for people with a learning disability and mental health problem to inform recommendations in this area. Therefore statements regarding these areas have been developed to be assessed by the group through the nominal group technique.

Statements are split into 4 sections:

1. Structures, training and supervision to support practitioners in the effective delivery of interventions (RQ4.6) (p. 2)
2. Models or support for transition between services (RQ4.2) (p. 2)
3. Coordination and communication between key persons and services in the life of a person with LD and MH problems (RQ4.3) (p. 3)
4. Engaging the family and staff/advocate of people with LD in the design, implementation and monitoring of interventions for that person’s mental health problems (RQ4.4) (p. 3)

 *(Please note that no re-rating is required for* Improving accessibility of services *or for* Engaging and empowering service users with LD in the design, implementation and monitoring of interventions for that person’s mental health problems *as there was sufficient agreement in those areas)*

Please ensure you have checked both sides of each sheet of paper, so that no items are missed.

For each of the statements please indicate your agreement as to their appropriateness and utility by circling one number in each row. The scale works as follows:

**Number 1**: Strongly disagree with this adaptation.

**Number 5**: Neither agree nor disagree.

**Number 9**: Strongly agree that this is a useful and appropriate adaptation.

There is also room to provide comments, if you wish.

|  |
| --- |
| **Structures, training and supervision to support practitioners in the effective delivery of interventions** |
| **Statements relating to structures, training and supervision to support practitioners in the effective delivery of interventions.** | **Scale** |
| **Strongly disagree** |  |  |  | **Strongly agree** |
| 1. Services for people with a learning disability **should work closely** with services for people with a learning disability and a mental health problem, if possible, in order to facilitate co-working and joined-up service provision.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. To prevent people with a **mild** learning disability and a mental health problem from falling ‘between the gaps’ of different services, care should generally be provided within mainstream mental health services with staff who have appropriate specialist training in working with people with learning disabilities.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. Specific dedicated beds should be provided for people with a learning disability and a mental health problem who require an acute admission.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. Generic psychological treatment services (for example, IAPT) should have the competence to be able to delivery treatment to people with **mild** LD, **calling on specialist support when needed**.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |
| 1. Generic MH services should have the competence to be able to delivery treatment to people with **mild** LD.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |

|  |
| --- |
| **Models or support for transition between services**  |
| **Statements relating to general principles for improving transition between services for people with a learning disability and a mental health problem.** | **Scale** |
| **Strongly disagree** |  |  |  | **Strongly agree** |
| 1. For people with a learning disability and a mental health problem **who needs ongoing care**, **the referring organisation should ensure that they do not discharge the person before another organisation has accepted the referral**.
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Comments: |