NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

Health and social care directorate

Quality standards and indicators

Briefing paper

Quality standard topic: Mental health problems in people with learning disabilities

Output: Prioritised quality improvement areas for development.

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Contents

1 Introduction

This briefing paper presents a structured overview of potential quality improvement areas for mental health problems in people with learning disabilities. It provides the Committee with a basis for discussing and prioritising quality improvement areas for development into draft quality statements and measures for public consultation. This is a contemporaneous Quality Standard which is being drafted from a draft guideline.

1.1 Structure

This briefing paper includes a brief description of the topic, a summary of each of the suggested quality improvement areas and supporting information.

If relevant, recommendations selected from the key development source below are included to help the Committee in considering potential statements and measures.

1.2 Development source

The key development source referenced in this briefing paper is:

Mental health problems in people with learning disabilities. NICE draft guideline NGXX (publication date expected in September 2016)

2 Overview

2.1 Focus of quality standard

This quality standard will cover the prevention, assessment and management of mental health problems in people with learning disabilities in health, social care, educational, forensic and criminal justice settings. It will also cover family members, carers and care workers.

2.2 Definitions

Learning disabilities

The Department of Health, in their report Valuing people: a new strategy for learning disability for the 21st century (Department of Health, 2001), uses the term 'learning disabilities' when the following 3 core criteria are present:

- a significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with
- a reduced ability to cope independently (impaired social functioning)

- which started before adulthood, with a lasting effect on development.

Some definitions of learning disabilities also require the person to have an IQ of less than 70, such as The International Classification of Diseases (ICD-10) Classification of Mental and Behavioural Disorders (World Health Organization, 2010). IQs are measured by intelligence tests, which allow a person's scores to be compared with the range of scores achieved by large numbers of people on the same test. However, it must be remembered that an IQ score does not give any information about a person's social, medical, educational and personal needs, nor what help and support the person might need.

Mental health problems

Throughout Mental health problems in people with learning disabilities. NICE draft guideline NGXX (2016-in development) and this Quality Standard we use the term 'mental health problems', and intend it to be synonymous with terms such as mental health needs, mental ill-health, mental health conditions, or mental disorders. The World Health Organisation defines mental disorders as 'a broad range of problems, with different symptoms, [...] generally characterized by some combination of abnormal thoughts, emotions, behaviour and relationships with others.'

This guideline addresses, for people with learning disabilities, the mental disorders included in the ICD-10 classification system (World Health Organization, 2010): common mental disorders (depression, and anxiety disorders), psychoses (schizophrenia, and bipolar disorder), dementias, eating disorders, alcohol and substance misuse, attachment disorders, and sexually inappropriate behaviour, and also other neuro-developmental conditions (autism, and attention deficit hyperactivity disorders [ADHD] and any associated mental health problems).

Problem behaviours (challenging behaviour, aggressive behaviour, destructive behaviour, and/or self-injurious behaviour) are not addressed in this quality standard, as they are the focus of a dedicated NICE quality standard on challenging behaviour and learning disabilities (NICE, 2015).

2.3 Prevalence

Learning disabilities

According to the School Census conducted in England each year, in 2014, 2.1% of children and young people attending state school had learning disabilities; 1.6% of children had moderate learning disabilities, 0.4% had severe learning disabilities, and 0.1% had profound and multiple learning disabilities (ONS, 2014). The collection of information on children with special educational needs (SEN) changed in 2015, with a new category of children requiring SEN Support, a combination of the previous School Action Plus and School Action stages in the assessment of SEN

(previously, information on type of SEN was only collected for children at School Action Plus). This wider classification of SEN has given a higher figure of 3.6% of children and young people with learning disabilities; 3.1% with moderate learning disabilities, 0.4% with severe learning disabilities, and 0.1% with profound and multiple (Hatton et al., 2016). According to information provided by General Practices in England in 2014 as part of their contractual arrangements with the Government, 0.5% of their registered patients aged 18 and over had learning disabilities.

Mental health problems

Mental health problems are very common, with 1 in 4 people experiencing mental health problems in their lifetime (McManus et al., 2009). Mental health problems contribute to 13% of the global burden of disease, much more than both cardiovascular disease and cancer (Collins et al., 2011; World Health Organization, 2008). Depression alone is the third leading contributor to the global disease burden, and in the equivalent of every 7 seconds, someone develops dementia (Ferri, 2005). Mental health problems in people with learning disabilities are even more common than in the rest of the population with a point prevalence of about 30% (Cooper et al., 2007b; Emerson & Hatton, 2007).

Some specific types of mental health problems are notably more common in people with learning disabilities than in other people, including schizophrenia (Cooper et al., 2007c; Turner, 1989), bipolar disorder (Cooper et al., 2007b), dementia (Cooper, 1997a; Strydom, 2007), ADHD (Emerson & Hatton, 2007), and pica. Autism is considerably more common in people with learning disabilities (Baird et al., 2006; Emerson & Baines, 2010; Emerson & Hatton, 2007). Indeed, prevalence rates of mental health problems for children and young people with learning disabilities have been reported to be higher than for other children and young people for 27 out of 28 ICD-10 diagnostic categories, and statistically significantly so for 20 of these 28 comparisons (Emerson & Hatton, 2007).

For people with learning disabilities, their most common types of experienced mental health problems are depression (Cooper et al., 2007f), anxiety disorders (Emerson & Hatton, 2007; Reid et al., 2011), and also autism (Baird et al., 2006; Emerson & Hatton, 2007), and in adults but not children or young people, schizophrenia (Cooper et al., 2007c; Turner, 1989).

Despite the high prevalence of mental health problems, they are often not recognised in people who have learning disabilities. This can be due to presumptions around the person’s behaviour and symptoms being attributed to their learning disabilities, or changes in their presentation not being noticed by carers. This can result in prolonged distress for the person with learning disabilities.

2.4 National Outcome Frameworks

Tables 1–3 show the outcomes, overarching indicators and improvement areas from the frameworks that the quality standard could contribute to achieving.

Table 1 The Adult Social Care Outcomes Framework 2015–16

Domain	Overarching and outcome measures
1 Enhancing quality of life for people with care and support needs	***Overarching measure*** 1A Social care-related quality of life** ***Outcome measures*** **People manage their own support as much as they wish, so they are in control of what, how and when support is delivered to match their needs** 1B Proportion of people who use services who have control over their daily life 1C Proportion of people using social care who receive self-directed support, and those receiving direct payments **Carers can balance their caring roles and maintain their desired quality of life** 1D Carer-reported quality of life** **People are able to find employment when they want, maintain a family and social life and contribute to community life, and avoid loneliness or isolation** 1E Proportion of adults with a learning disability in paid employment** 1F Proportion of adults in contact with secondary mental health services in paid employment** 1G Proportion of adults with a learning disability who live in their own home or with their family* 1H Proportion of adults in contact with secondary mental health services living independently, with or without support* 1I Proportion of people who use services and their carers, who reported that they had as much social contact as they would like
2 Delaying and reducing the need for care and support	***Overarching measure*** 2A Permanent admissions to residential and nursing care homes, per 100,000 population ***Outcome measures*** **Everybody has the opportunity to have the best health and wellbeing throughout their life, and can access support and information to help them manage their care needs** **Earlier diagnosis, intervention and reablement means that people and their carers are less dependent on intensive services** 2B Proportion of older people (65 and over) who were still at home 91 days after discharge from hospital into reablement/rehabilitation services* **When people develop care needs, the support they receive takes place in the most appropriate setting and enables them to regain their independence** 2C Delayed transfers of care from hospital, and those which are attributable to adult social care *Placeholder 2F Dementia – a measure of the effectiveness*

	*of post-diagnosis care in sustaining independence and improving quality of life***
3 Ensuring that people have a positive experience of care and support	***Overarching measure*** **People who use social care and their carers are satisfied with their experience of care and support services** 3A Overall satisfaction of people who use services with their care and support 3B Overall satisfaction of carers with social services *Placeholder 3E The effectiveness of integrated care* ***Outcome measures*** **Carers feel that they are respected as equal partners throughout the care process** 3C The proportion of carers who report that they have been included or consulted in discussions about the person they care for **People know what choices are available to them locally, what they are entitled to, and who to contact when they need help** 3D The proportion of people who use services and carers who find it easy to find information about support **People, including those involved in making decisions on social care, respect the dignity of the individual and ensure support is sensitive to the circumstances of each individual** This information can be taken from the Adult Social Care Survey and used for analysis at the local level.
Alignment with NHS Outcomes Framework and/or Public Health Outcomes Framework * Indicator is shared ** Indicator is complementary Indicators in italics in development	

Table 2 NHS Outcomes Framework 2016–17

Domain	Overarching indicators and improvement areas
1 Preventing people from dying prematurely	**Reducing premature mortality in people with mental illness** 1.5 i Excess under 75 mortality rate in adults with serious mental illness* *ii Excess under 75 mortality rate in adults with common mental illness** *iii Suicide and mortality from injury of undetermined intent among people with recent contact from NHS services*** **Reducing premature death in people with a learning disability** *1.7 Excess under 60 mortality rate in adults with a learning disability*
2 Enhancing quality of life for people with long-term conditions	***Overarching indicator*** 2 Health-related quality of life for people with long-term conditions** ***Improvement areas*** **Ensuring people feel supported to manage their condition** 2.1 Proportion of people feeling supported to manage their condition **Improving functional ability in people with long-term conditions** 2.2 Employment of people with long-term conditions*, ** **Enhancing quality of life for carers** 2.4 Health-related quality of life for carers** **Enhancing quality of life for people with mental illness** 2.5 i Employment of people with mental illness** *ii Health-related quality of life for people with mental illness*** **Enhancing quality of life for people with dementia** 2.6 i Estimated diagnosis rate for people with dementia* *ii A measure of the effectiveness of post-diagnosis care in sustaining independence and improving quality of life*, *** **Improving quality of life for people with multiple long-term conditions** *2.7 Health-related quality of life for people with three or more long-term conditions***
3 Helping people to recover from episodes of ill health or following injury	***Overarching indicators*** ***Improvement areas*** **Improving outcomes from planned treatments** 3.1 Total health gain as assessed by patients for elective procedures *ii Psychological therapies* *iii Recovery in quality of life for patients with mental illness*

4 Ensuring that people have a positive experience of care	***Overarching indicators*** 4a Patient experience of primary care i GP services ii GP Out-of-hours services 4b Patient experience of hospital care 4c *Friends and family test* *4d Patient experience characterised as poor or worse* *I Primary care* *ii Hospital care* ***Improvement areas*** **Improving access to primary care services** 4.4 Access to i GP services **Improving experience of healthcare for people with mental illness** *4.7 Patient experience of community mental health services* **Improving children and young people's experience of healthcare** *4.8 Children and young people's experience of inpatient services* **Improving people's experience of integrated care** *4.9 People's experience of integrated care***
Alignment with Adult Social Care Outcomes Framework and/or Public Health Outcomes Framework * Indicator is shared ** Indicator is complementary Indicators in italics in development	

Table 3 Public health outcomes framework for England, 2016-19

Domain	Objectives and indicators
1 Improving the wider determinants of health	***Objective*** Improvements against wider factors that affect health and wellbeing and health inequalities ***Indicators*** 1.6 Adults with a learning disability/in contact with secondary mental health services who live in stable and appropriate accommodation* 1.7 Proportion of people in prison aged 18 or over who have a mental illness 1.8 Employment for those with long-term health conditions including adults with a learning disability or who are in contact with secondary mental health services*,**
4 Healthcare public health and preventing premature mortality	***Objective*** Reduced numbers of people living with preventable ill health and people dying prematurely, whilst reducing the gap between communities ***Indicators*** 4.9 Excess under 75 mortality rate in adults with serious mental illness* 4.10 Suicide rate 4.13 Health-related quality of life for older people
Alignment with Adult Social Care Outcomes Framework and/or NHS Outcomes Framework * Indicator is shared ** Indicator is complementary Indicators in italics in development	

3 Summary of suggestions

3.1 Responses

In total 14 stakeholders responded to the 2-week engagement exercise 07/03/16-20/04/16.

Stakeholders were asked to suggest up to 5 areas for quality improvement. Specialist committee members were also invited to provide suggestions. The responses have been merged and summarised in table 4 for further consideration by the Committee.

Full details of all the suggestions provided are given in appendix 2 for information.

Table 4 Summary of suggested quality improvement areas

Suggested area for improvement	Stakeholders
Organisation and delivery of support • Organising effective care • Staff training and supervision	BCUHB, MNP, NASS, NHSE, SCM
Involving people with learning disabilities, and their family members, carers or care workers, in mental health assessment and treatment • Communication • Consent, capacity and decision-making	NASS, BCUHB, SCM
Support and interventions for family members and carers	SCM
Assessment • Conducting a mental health assessment	MNP, CPNHST
Annual health check	SCM
Psychological interventions • Specific psychological interventions	CBF, BCUHB
Pharmacological interventions	LWH, SCM
Occupational interventions	BCUHB

AHL, Action on Hearing Loss
BCUHB, Betsi Cadwaradr University Health Board
CBF, The Challenging Behaviour Foundation
CPNHST, Calderstones Partnership NHS Trust
LWH, Living with Harmony
MNP, Mencap
NAS, The National Autistic Society
NASS, The National Association of Independent Schools & Non-Maintained Special Schools
NHSE, NHS England
RCPCH, Royal College of Paediatrics and Child Health
SCM, Specialist Committee Member
SWYP_NHSFT, South West Yorkshire Partnership NHS Foundation Trust

3.2 Identification of current practice evidence

Bibliographic databases were searched to identify examples of current practice in UK health and social care settings; 1775 papers were identified for mental health problems in people with learning disabilities. In addition, 5 papers were suggested by stakeholders at topic engagement.

Of these papers, 5 have been included in this report and are included in the current practice sections where relevant. Appendix 1 outlines the search process.

4 Suggested improvement areas

4.1 Organisation and delivery of support

4.1.1 Summary of suggestions

Organising effective care

A stakeholder reported a gap between mental health and learning disability services with a need for integration and equitable access to mental health services. The implementation of a designated leadership team and a key worker was supported to connect services, lead and co-ordinate ongoing care and enable swift diagnosis.

Need for local access to services was highlighted to prevent vulnerable mental health with learning disability people being placed in remote units out away from their local area.

Staff training and supervision

A stakeholder reported a current lack of trained Child and Adolescent Mental Health Services (CAMHS) practitioners in supporting people with Special Educational Needs and Disability (SEND). This can lead to difficulties accessing suitable CAMHS in a timely manner.

Staff with appropriate, up to date training, knowledge and skills was raised as key by a stakeholder to provide quality person-centred care and support or refer as appropriate in a timely manner.

4.1.2 Selected recommendations from development source

Table 5 below highlights recommendations that have been provisionally selected from the development source(s) that may support potential statement development. These are presented in full after table 5 to help inform the committee's discussion.

Table 5 Specific areas for quality improvement

Suggested quality improvement area	Suggested source guidance recommendations
Organisation and delivery of support	**Organising effective care** NICE NGXX Recommendations 1.2.2 and 1.2.6

Organisation and delivery of support	Staff training and supervision NICE NGXX Recommendation 1.2.9

Organising effective care

NICE NGXX – Recommendation 1.2.2

The designated leadership team should ensure that care pathways:

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

NICE NGXX – Recommendation 1.2.6

For people with learning disabilities who need acute inpatient treatment for a serious mental illness, provide treatment:

- within a locally available service where possible **and**
- with staff who are skilled and knowledgeable in the care and treatment of mental health problems in people with learning disabilities.

NICE NGXX – Recommendation 1.2.8

All people with learning disabilities and a serious mental illness should have a key worker who:

- coordinates all aspects of care, including safeguarding concerns and risk management
- helps services communicate with the person and their family members, carers or care workers (as appropriate) clearly and promptly, in a format and language suited to the person's needs and preferences
- monitors the implementation of the care plan and its outcomes.

Staff training and supervision

NICE NGXX – Recommendation 1.2.9

Health, social care and education services should train all staff who may come into contact with people with learning disabilities to be aware:

- that people with learning disabilities are at increased risk of mental health problems

- that mental health problems may develop and present in different ways from people without learning disabilities, and the usual signs or symptoms may not be observable or reportable
- that people with learning disabilities can develop mental health problems for the same reasons as people without learning disabilities (for example, because of financial worries, bereavement or relationship difficulties)
- that mental health problems are commonly overlooked in people with learning disabilities
- where to refer people with learning disabilities and suspected mental health problems.[1]

4.1.3 Current UK practice

Organising effective care

Royal College of Psychiatrists (2013) faculty report[2] outlined current community-based services for people with intellectual disability with significant regional variation in practice.

The 2015 Learning Disability Census[3] data reported average distance patient from home to inpatient ward. This has not changed significantly between all 3 census collections.

Also Public Health England (2013)[4] reported that 33% of inpatient people with learning disabilities were hospitalised within 20 kilometres of their home, but 37% were more than 50 kilometres away from home.

Staff training and supervision

Royal College of Psychiatrists (2013) faculty report[2] highlighted a need for improved staff training in the assessment of those with a dual diagnosis of intellectual disability and mental illness within mainstream mental health services.

4.1.4 Resource impact assessment

This area is likely to have some resource implications. This is as result of the potential need to restructure services in some areas and to provide training to staff.

[1] This recommendation and recommendations 1.5.5, 1.6.18, 1.7.3 and 1.7.4 update and replace recommendation 1.3.3.2 in the NICE guideline on supporting people with dementia and their carers in health and social care.
[2] Royal College of Psychiatrists (2013) People with learning disability and mental health, behavioural or forensic problems: the role of in-patient services: faculty report ID/03
[3] Learning Disability Census: England 2015, experimental statistics
[4] Public Health England (2013) People with Learning Disabilities in England

Training costs could be minimised where it is delivered in-house or sourced from freely available sources online.

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

4.2.1 Summary of suggestions

Communication

A stakeholder highlighted the importance of communication as some children and young people with Special Educational Needs and Disability (SEND) can experience difficulties in communication and many CAMHS professionals are inexperienced in engaging with this group.

Consent, capacity and decision-making

A stakeholder raised that the lack of communication can mean the duty to incorporate the views and wishes of the children and young people into their mental health service design and delivery is not considered.

Easy read or accessible information regarding mental health conditions, health promotion and the Mental Health Act was also supported to enable self-management.

Involving family members, carers and care workers

Family or carer involvement was encouraged by a stakeholder as they can initially detect a decline in mental health and also can provide the day to day pharmacological and psychological support after diagnosis.

4.2.2 Selected recommendations from development source

Table 6 below highlights recommendations that have been provisionally selected from the development source(s) that may support potential statement development. These are presented in full after table 6 to help inform the Committee's discussion.

Table 6 Specific areas for quality improvement

Suggested quality improvement area	Selected source guidance recommendations
Involving people with learning disabilities, and their family members, carers or care workers, in mental health assessment and treatment	**Communication** NICE NGXX Recommendation 1.3.1
Involving people with learning disabilities, and their family members, carers or care workers, in mental health assessment and	**Consent, capacity and decision-making** NICE NGXX Recommendation 1.3.2

treatment	
Involving people with learning disabilities, and their family members, carers or care workers, in mental health assessment and treatment	**Involving family members, carers and care workers** NICE NGXX Recommendation 1.3.4

Communication

NICE NGXX Recommendation 1.3.1

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

- speak to the person directly rather than talking about or over them
- use clear, straightforward and unambiguous language
- assess whether communication aids or someone familiar with the person's communication methods are needed
- make adjustments to accommodate sensory impairments
- explain the content and purpose of every meeting or session
- use concrete examples, visual imagery, practical demonstrations and role play to explain concepts
- communicate at a pace that is comfortable for the person, and arrange longer or additional meetings or treatment sessions if needed
- use different methods and formats for communication (written, visual, verbal, or a combination of these), depending on the person's preferences (see the Accessible Information Standard for guidance on ensuring people with learning disabilities receive information in formats they can understand)
- regularly check the person's understanding
- summarise and explain the conclusions of every meeting or session
- check that the person has communicated what they wanted.

Consent, capacity and decision-making

NICE NGXX Recommendation 1.3.2

Assess the person's capacity to make decisions throughout assessment, care and treatment for the mental health problem on a decision-by-decision basis, in accordance with the Mental Capacity Act and supporting codes of practice (see Your care). Help people make decisions by ensuring that their communication needs are met (see recommendation 1.3.1) and involving a family member, carer or care worker (as appropriate).

Involving family members, carers and care workers

NICE NGXX Recommendation 1.3.4

Encourage and support family members, carers and care workers (as appropriate) to be actively involved throughout the assessment, care and treatment of the person's mental health problem, apart from in exceptional circumstances when an adult or young person with decision-making capacity has said that they do not want their family members, carers or care workers involved.

4.2.3 Current UK practice

Communication

Foundation for People with Learning Disabilities [5](2014) conducted a national survey on quantitative and qualitative information on current experience. It was concluded that 67% of people with learning disabilities who were surveyed said they had no written information in easy read and they felt that the information and advice was not accessible.

Consent, capacity and decision-making

No published studies on current practice were highlighted for this suggested area for quality improvement; this area is based on stakeholder's knowledge and experience.

Involving family members, carers and care workers

The 2015 Learning Disability Census[6] data reported that 2,085 inpatients (70%) had family involved in their care plan discussions which is consistent with 2014 findings.

4.2.4 Resource impact assessment

There are no significant resource implications expected.

[5] Foundation for People with Learning Disabilities (2014) -Feeling Down Improving the mental health of people with learning disabilities
[6] Learning Disability Census: England 2015, experimental statistics

4.3 Support and interventions for family members and carers

4.3.1 Summary of suggestions

Support and interventions for family members and carers

Stakeholders highlighted that parents caring for children and adults with learning disabilities are at increased risk of mental health problems and stress. In turn, a stakeholder reported that poor parental psychological well-being is associated with poorer development and other outcomes (including mental health problems) in children and adults with learning disabilities.

4.3.2 Selected recommendations from development source

Table 7 below highlights recommendations that have been provisionally selected from the development source(s) that may support potential statement development. These are presented in full after table 7 to help inform the Committee's discussion.

Table 7 Specific areas for quality improvement

Suggested quality improvement area	Selected source guidance recommendations
Support and interventions for family members and carers	NICE NGXX Recommendations 1.4.1-1.4.3

Support and interventions for family members and carers

NICE NGXX Recommendation 1.4.1

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

- a formal assessment of their own needs (including their physical and mental health)
- short breaks and other respite care.

NICE NGXX Recommendation 1.4.2

When providing support to family members (including siblings) and carers:

- recognise the potential impact of living with or caring for a person with learning disabilities and a mental health problem
- explain how to access:

  - family advocacy

- family support and information groups

- disability-specific support groups for family members or carers

- provide skills training and emotional support, or information about how to access these, to help them take part in and support interventions for the person with learning disabilities and a mental health problem.

NICE NGXX Recommendation 1.4.3

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

- interventions in line with the NICE guidelines on specific mental health problems (see mental health and behavioural conditions on the NICE website) **or**
- referral to a mental health professional who can provide interventions in line with NICE guidelines.

4.3.3 Current UK practice

Support and interventions for family members and carers

No published studies on current practice were highlighted for this suggested area for quality improvement; this area is based on stakeholder's knowledge and experience.

4.3.4 Resource impact assessment

No significant resource implications are expected.

4.4 Assessment

4.4.1 Summary of suggestions

Conducting a mental health assessment

Stakeholders highlighted the need for assessment which would positively reduce diagnostic overshadowing which is the tendency to attribute all other problems to a diagnosis, thereby leaving other co-existing conditions undiagnosed. It was reported that there is a current lack of appropriate assessment measures to identify mental health issues in people with a learning disability.

Risk assessment was supported specifically for people with learning disability with depression and suicide risk.

4.4.2 Selected recommendations from development source

Table 8 below highlights recommendations that have been provisionally selected from the development source(s) that may support potential statement development. These are presented in full after table 8 to help inform the Committee's discussion.

Table 8 Specific areas for quality improvement

Suggested quality improvement area	**Selected source guidance recommendations**
Assessment	**Conducting a mental health assessment** NICE NGXX Recommendations 1.6.1, 1.6.4- 6.
Assessment	**Risk assessment** NICE NGXX Recommendation 1.6.19

Conducting a mental health assessment

<u>NICE NGXX Recommendation 1.6.1</u>
A professional with expertise in mental health problems in people with learning disabilities should coordinate the mental health assessment, and conduct it with:

- the person with the mental health problem, in a place familiar to them if possible, and help them to prepare for it if needed
- the person's family members, carers or care workers (as appropriate)

- other professionals (if needed) who are competent in using a range of assessment tools and methods with people with learning disabilities and mental health problems.

NICE NGXX Recommendation 1.6.4

When conducting mental health assessments, be aware:

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

NICE NGXX Recommendation 1.6.5

When conducting mental health assessments, take into account:

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

NICE NGXX Recommendation 1.6.6

During mental health assessments:

- establish specific areas of need to focus on
- assess all potential psychopathology, and not just the symptoms and signs that the person and their family members, carers or care workers first report
- describe the nature, duration and severity of the presenting mental health problem
- review psychiatric and medical history, past treatments and response
- review physical health problems and any current medication
- review the nature and degree of the learning disabilities, including behavioural phenotypes (for example, autism and Prader–Willi syndrome)
- assess the person's family and social circumstances and environment, and recent life events
- assess the level of drug or alcohol use as a potential problem in itself and as a factor contributing to other mental health problems
- establish or review a diagnosis using:
  - a classification system, such as those adapted for learning disabilities (for example the Diagnostic Manual – Intellectual Disability [DM-ID] or Diagnostic Criteria for Psychiatric Disorders for Use with Adults with Learning Disabilities/Mental Retardation [DC-LD]) or
  - problem specification
- assess whether a risk assessment is needed (see recommendation 161.6.19).

Risk assessment

NICE NGXX Recommendation 1.6.19
When conducting risk assessments with people with learning disabilities and mental health problems, assess:

- risk to self
- risk to others (including sexual offending)
- risk of self-neglect
- vulnerability to exploitation
- potential triggers
- causal and maintaining factors
- whether safeguarding protocols should be implemented
- the likelihood and severity of any particular risk.

4.4.3 Current UK practice

Conducting a mental health assessment

No published studies on current practice were highlighted for this suggested area for quality improvement; this area is based on stakeholder's knowledge and experience.

Risk assessment

The 2015 Learning Disability Census[7] data reported that 2,195 patients (73%) were not recorded as having any risks that were severe enough to require hospital treatment, with 455 patients (15%) only having 1 risk. It was however noted that the cumulative effect of several lesser risks could have an impact on overall assessment but this cannot be determined from this data.

4.4.4 Resource impact assessment

No significant resource implications are expected.

[7] Learning Disability Census: England 2015, experimental statistics

4.5 Annual health check

4.5.1 Summary of suggestions

Stakeholders highlighted the importance of including a mental health assessment in annual health checks for adults and children with learning disabilities as evidence suggests that these checks can directly impact on life expectancy and mortality rates.

4.5.2 Selected recommendations from development source

Table 9 below highlights recommendations that have been provisionally selected from the development source(s) that may support potential statement development. These are presented in full after table 9 to help inform the Committee's discussion.

Table 9 Specific areas for quality improvement

Suggested quality improvement area	Selected source guidance recommendations
Annual health check	**Annual health check** NICE NGXX Recommendations 1.7.1 and1.7.3

Annual health check

NICE NGXX Recommendation 1.7.1
GPs should offer an annual health check using a standardised template to all adults with learning disabilities, and all children and young people with learning disabilities who are not having annual health checks with a paediatrician.

NICE NGXX Recommendation 1.7.3

Include the following in annual health checks:

- a review of any known or suspected mental health problems and how they may be linked to any physical health problems
- a physical health review, including assessment for the conditions and impairments which are common in people with learning disabilities
- a review of all current interventions, including medication and related side effects, adverse events, interactions and adherence

- an agreed and shared care plan for managing any physical health problems (including pain)[8]

4.5.3 Current UK practice

Annual health check

Public Health England 2013[9] estimated that there are 177,389 (20%) adults deemed eligible for annual health checks.

Table 10. Uptake of Annual Health Checks for People with Learning Disabilities 2008 to 2009 to 2011 to 2012 (and percentage change from previous year)

	2008 to 20009	2009 to 2010	2010 to 2011 (revised)	2011 to 2012 (revised)	2012 to 2013
Number of people who received a health check	27,011	58,919 (+118%)	73,068 (+24%)	86,134 (+18%)	92,329 (+7%)
Number of people identified as eligible to receive a health check	118,230	145,130 (+23%)	153,021 (+5%)	162,991 (+7%)	177,389 (+9%)
% of identified eligible people who received a health check	23%	41% (+78%)	48% (+18%)	53% (+11%)	52% (-1%)

The number of people having a learning disabilities health check has risen each year, though by low amounts. The number of people reported as eligible has also risen annually.

The 2015 Learning Disability Census 2015[10] data indicates an increase in independent face to face assessments with care plan discussions for 1,150 (38%) in 2015 received compared with 1,000 patients (31%) in 2014.

4.5.4 Resource impact assessment

There is no significant resource implications expected because annual health checks are already funded through enhanced services.

[8] This recommendation and recommendations 1.2.9, 1.5.5, 1.6.18 and 1.7.4 update and replace recommendation 1.3.3.2 in the NICE guideline on supporting people with dementia and their carers in health and social care.
[9] Public Health England (2013) People with Learning Disabilities in England
[10] Learning Disability Census: England 2015, experimental statistics

4.6 Psychological interventions

4.6.1 Summary of suggestions

4.6.2 Selected recommendations from development source

Specific psychological interventions

A stakeholder cited growing evidence of the effectiveness of psychotherapy and counselling for people with learning disabilities.

Parental training programmes was supported by a stakeholder.

Table 11 below highlights recommendations that have been provisionally selected from the development source(s) that may support potential statement development. These are presented in full after table 11 to help inform the Committee's discussion.

Table 11 Specific areas for quality improvement

Suggested quality improvement area	**Selected source guidance recommendations**
Psychological interventions	**Specific psychological interventions** NICE NGXX Recommendations 1.8.5, 1.8.6 and 1.8.9 -1.8.9

Specific psychological interventions

NICE NGXX Recommendation 1.8.5

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

NICE NGXX Recommendation 1.8.6

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

NICE NGXX Recommendation 1.8.8

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

NICE NGXX Recommendation 1.8.9

Parent training programmes should:

- be delivered in groups of parents or carers
- be accessible (for example, take place outside normal working hours or in community settings with childcare facilities)
- focus on developing communication and social functioning skills
- typically consist of 8 to 12 sessions lasting 90 minutes
- follow the relevant treatment manual
- use all of the necessary materials to ensure consistent implementation of the programme
- seek parent feedback.

4.6.3 Current UK practice

Specific psychological interventions

Parkes et al (2006)[11]conducted a case note review relating to 100 sequential patient episodes to identify referral characteristics and outcomes for people with intellectual disabilities. It was concluded that 81 people of 100 with a range of intellectual disabilities from mild to severe were assessed as suitable for therapy; 66 were eligible for individual, art or group therapy.

4.6.4 Resource impact assessment

Experts suggest that psychological interventions are already being offered both in learning disabilities services and in improving access to psychological therapies. However, they also suggest the interventions are not currently available sufficiently across the country and there is a lack of trained therapists in many Trusts. Therefore there may be some additional costs incurred to ensure any potential increase in demand for interventions and training is met.

[11] Parkes et al- Referrals to an Intellectual Disability Psychotherapy Service in an Inner City Catchment Area- Journal of Applied Research in Intellectual Disabilities, 20, 373-378

4.7 Pharmacological interventions

4.7.1 Summary of suggestions

4.7.2 Selected recommendations from development source

Pharmacological interventions

A stakeholder raised concern of medicine management by the person with learning disabilities as being dangerously limited with carers lacking competence or confident to administer.

It was highlighted that medication should be regularly reviewed in line with the person's needs and the benefits. Some mental health patients will appropriately require treatment but many are being medicated purely based on their learning disability. It was reported that these patients will be on high dose medication for many years without clear rationale or evidence base for what this medication is trying to achieve.

Table 12 below highlights recommendations that have been provisionally selected from the development source(s) that may support potential statement development. These are presented in full after table 12 to help inform the Committee's discussion.

Table 12 Specific areas for quality improvement

Suggested quality improvement area	Selected source guidance recommendations
Pharmacological interventions	**Pharmacological interventions** NICE NGXX Recommendations 1.9.1, 1.9.4 and 1.9.7.

Pharmacological interventions

NICE NGXX Recommendation 1.9.1

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

NICE NGXX Recommendation 1.9.4

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

NICE NGXX Recommendation 1.9.7

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

- reduce or discontinue long-term prescriptions of antipsychotic drugs
- consider referral to a psychiatrist experienced in working with people with learning disabilities and mental health problems
- annually document the reasons for continuing the prescription if it is not reduced or discontinued.

4.7.3 Current UK practice

Pharmacological interventions

The 2015 Learning Disability Census[12] reported on 89 provider organisation responses on behalf of 3,000 patients. It was reported 2,155 patients (72%) received regular antipsychotic medication or as and when needed in the 28 days prior to census, this compares to a slight decrease in 73% in 2014 and 68% in 2013.

4.7.4 Resource impact assessment

There are no significant additional resource implications expected.

[12] Learning Disability Census: England 2015, experimental statistics

4.8 Occupational interventions

4.8.1 Summary of suggestions

4.8.2 Selected recommendations from development source

A stakeholder reported that in light of a cultural change to community support, the role of local community learning disability services will have to be strengthened in primary care to minimise the risk of relapse and/or people going into crisis.

Table 13 below highlights recommendations that have been provisionally selected from the development source(s) that may support potential statement development. These are presented in full after table 13 to help inform the Committee's discussion.

Table 13 Specific areas for quality improvement

Suggested quality improvement area	Selected source guidance recommendations
Occupational interventions	**Occupational interventions** NICE NGXX Recommendation 1.11.1

Occupational interventions

NICE NGXX Recommendation 1.11.1

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

- engage in community activities, such as going to a library or sports centre
- access local community resources, such as those provided at day centres
- take part in leisure activities, such as hobbies, which are meaningful to the person.

Reasonable adjustments may be needed to do this, such as a buddy system, transport, or advising local facilities on accessibility.

4.8.1 Current UK practice

Occupational interventions

Public Health England 2013[13] reported that in regards to community social care services in England during 2012-2013:

- local authorities reported 114,265 adults with learning disabilities aged 18+ using some form of social care community service (with small but consistent year-on-year increases from 2005 to 2006)
- regarding day services there were 51,300 adults with learning disabilities using local authority funded day services (with small but consistent year-on-year decreases from 2005 to 2006). Local authorities spent £681.5 million on day services for adults with learning disabilities aged 18 to 64 years, a decrease of 4.5% from 2011 to 2012.

4.8.2 Resource impact assessment

There are no significant additional resource implications are expected.

[13] Public Health England (2013) People with Learning Disabilities in England

4.9 Additional areas

Summary of suggestions

The improvement areas below were suggested as part of the stakeholder engagement exercise. However they were felt to be either unsuitable for development as quality statements, outside the remit of this particular quality standard referral or require further discussion by the Committee to establish potential for statement development.

There will be an opportunity for the QSAC to discuss these areas at the end of the session on 2 June 2016.

Hearing Loss

A stakeholder highlighted the links between hearing loss and mental health. This is not mentioned in the guidance.

Autism

A stakeholder suggested including autism within the scope of this Quality Standard which is currently out of scope.

Links between education and health

A stakeholder suggested that greater links between education and health should be reflected in this Quality Standard. This is not mentioned in the guidance.

Dedicated mental health liaison nurse for learning disabilities

A stakeholder supported this role as relatively new with a number of positive care and support benefits. This is not mentioned in the guidance.

Dialectical behavioural therapy

A stakeholder highlighted the importance of Dialectical Behavioural Therapy as a psychological approach. This is not mentioned in the guidance.

Related QSs- Looked after children (QS31) and Learning disabilities: challenging behaviour (QS101)

Stakeholder highlighted a number of related QSs to this topic which are already published.

Provision of support for those with severe and complex mental health disorders and SEND.

A stakeholder referred to a 2014 NHS England CAMHS Tier 4 Report which identified a lack of suitable tier 4 beds for CYP with severe and complex mental health disorders via Tier 4 CAMHS Learning Disability Services. This is not mentioned in the guidance.

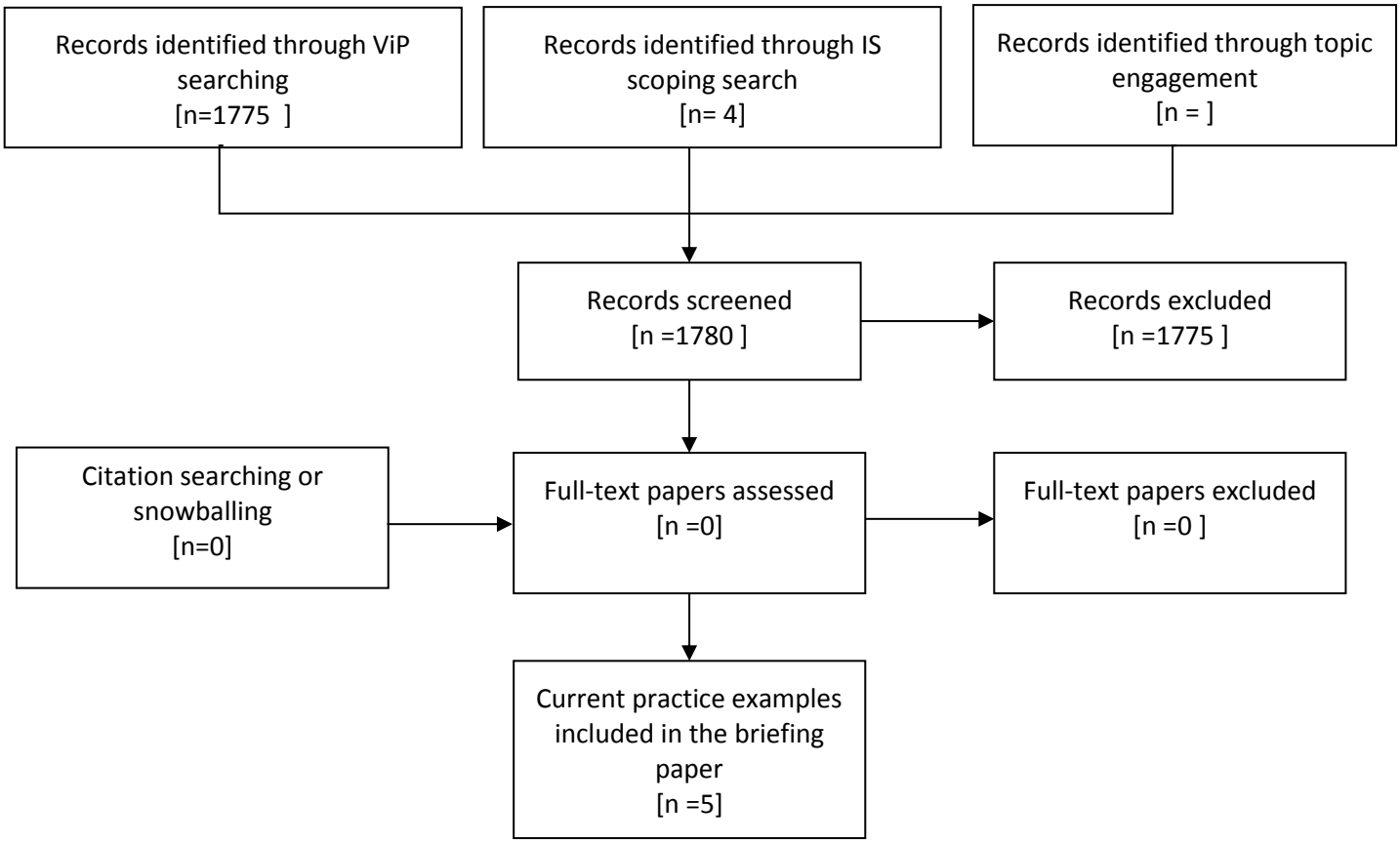
Care and treatment reviews (CTRs)

A stakeholder highlighted NHS England's programme of Care and Treatment Reviews (CTRs) of individual patients' care. These include rationales for hospital admission and treatment plans for future planning and to enhance quality of care. This is not mentioned in the guidance.

Designing, planning, delivery and reviewing of services

Decision making by children, young people and their parents or carers was also supported by a stakeholder in designing, planning, delivery and reviewing of services. This is not mentioned in the guidance.

Appendix 1: Review flowchart



Appendix 2: Suggestions from stakeholder engagement exercise – registered stakeholders

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
1.2 Organisation and delivery of support					
01	Mencap	Gap between Learning disability and mental health services	There is a mental health and learning disability service gap		Mental health and learning disability services are often separate, and do not always work together (Taylor et al., 2008). Additionally, mental health services are not always accessible to people with a learning disability. This can mean that there is a gap in provision for those who suffer from mental health problems and have a learning disability. There is evidence suggesting that people with a learning disability miss out on centrally funded initiatives such as IAPT and memory clinics (Davies, 2012; Kreose et al., 2012). Kreose and colleagues (2012) found that mental health nurses were unprepared for the needs of service users with a learning disability and some services unwilling to follow up patients long enough to ensure effective interventions. On the other hand, those with more severe learning disabilities and mental health problems will most likely present to learning disability services. It is important that front line workers in both these services are aware of the symptoms of mental health when presented by people with a learning disability. See National Development Team for inclusion (NDTi) briefing on how mental health services can become more accessible for people with a learning disability.
02	The National Association of Independent	Training of CAMHS professionals in supporting those with	Very few CAMHS practitioners are trained in the provision of support to	NASS schools – which provide support to children who often have	

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
	Schools & Non-Maintained Special Schools (NASS)	SEND.	those with SEND. The shortage of CAMHS/SEND cross-trained individuals often results in significant difficulties accessing suitable CAMHS provisions in a timely manner. The draft guidance demonstrates the paucity of evidence of effective assessment and treatment of mental health problems in children with SEND.	profound SEN and/or disabilities – frequently report huge frustration in accessing suitable CAMHS support, and know that the availability and accessibility of such services is inconsistent and variable. This has often resulted in schools employing, training and developing their own CAMHS staff. This works well for the school but means that valuable expertise is held in isolation of the wider system.	
03	Betsi Cadwaradr University Health Board (BCUHB)	Equitable access to generic mental health services	Equitable access to mental health services should enable service users to access the most appropriate service to meet their needs. Wherever possible and where reasonable adjustment can be made, people with learning disabilities should have access to mainstream services to get the	From personal experience mental health services will often be either reluctant or refuse to work with people with learning disabilities. Referrals to these services are often signposted back to learning disability services.	Current literature, such as Reasonably adjusted? (2012), Supporting Complex Needs (2006) and Feeling Down (2014) continue to find that people with learning disabilities and co-existing mental health issues are still often not receiving either the appropriate and/or quality of services they are entitled to or have the rights to receive. The National Service Framework (NSF) for mental health applies to all adults of working age. A person with a learning disability who has a mental illness should therefore expect to access services and be treated in the same way as anyone

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
			therapeutic intervention from professionals with the most appropriate training, skills, knowledge and expertise. Reasonable adjustments not only include removing physical barriers to accessing services, but importantly changing the ways in which services are delivered and ensuring that policies, procedures and staff training all enable services to work equally well for people with learning disabilities.	Betsi Cadwaladr University Health Board (BCUHB) have made significant progress with generic inpatient services and now have a specific policy to ensure equal access for people with learning disabilities, which is at the last stage of ratification; However community services continue to be less open to change. The Foundation for people with learning disabilities (2014) states that until recently there was reluctance from mainstream services to provide mental health support for adults with LD.	else. Together for Mental Health (2012) highlights the need to reduce inequalities for vulnerable groups with mental health needs, ensuring equitable access and provision of mental health services. The Winterbourne View Hospital Interim Report (2012) and The joint commissioning panel for mental health (2013) recommend that all local services should build an understanding of the reasonable adjustments needed, so that for people with learning disabilities who have a mental health problem can make use of local generic mental health beds. These recommendations are underpinned by the Disability Discrimination Act (2005) and Equality Act (2010), which specify that all public sector services have a legal duty to provide 'reasonable adjustments' for people with learning disabilities.
04	Betsi Cadwaradr University Health Board (BCUHB)	Ensuring service users are supported by staff with appropriate, up to date training, knowledge and skills	To ensure servicer users maintain optimum wellness, minimise risk of relapse and have a good quality of life it is essential that support staff have the relevant knowledge	There are a host of areas that will need to be addressed including: Person centred care and planning	A robust system of measures needs to be established with strategic direction from the national programme to avoid 'institutional' cultures from emerging in the community – we need to know that services are ensuring individuals have a choice over the support they receive, independence, and that it is delivered in a way that puts their interests front and

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
			and skill set to provide quality, progressive and person centred care and support.	Progressive care and support Workforce shortages Training needs Developing cultural competence Sharing expertise and good practice Combining knowledge and skills together around people	centre. Prevention has a key role to play here. This is not just about saving money; it is about managing peoples' needs and circumstances in a safe and cost effective manner. This ultimately means the extent of their need and with the right support they are able to become more independent. Time for Change -The Challenge Ahead (2016).
05	SCM1	Named lead professional	It is widely recognised that one of the difficulties people experience when accessing services is telling their stories lots of times. In recent engagement sessions I have led around service review families told us time and time again that it is confusing who they go to for what and that they feel they spend a lot of time coordinating care. Given that mental health problems are often difficult to assess and may be noticed much later in people with a LD joined up working and		

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
			coordination is key. The National Service model (building the right support), transforming care and the NICE Guidance for LD/MH states there should be a named professional who leads and coordinates the care someone receives. The reality of this is there is often a named lead professional in each agency, that they each only lead or coordinate the parts they are responsible for and that this then feels fragmented for the family. In times of service cuts we also see clinically that sometimes the named person is in 'name only' and may actually have very little input into the case.		
06	SCM1	Reasonable adjustments in mainstream mental health services	The national direction of travel is for people to be able to access mainstream services wherever possible. In order to do this services must make reasonable		

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
			adjustments. These adjustments should be available in advance of the person accessing the service and not waiting until someone tries to access services. The Green Light Toolkit for Mental Health develops and audit tool so that services can see if they are accessible. It is often the case that services do not feel equipped to work with people with LD and this makes access difficult. We know that MH problems may present differently in people with LD and may be harder to assess. We also know that reasonable adjustments such as longer appointments, same appointment times, accessible information, breaking down sessions etc can help but that clinically people with a learning disability do not always feel		

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
			accessing mental health services is easy for them		
07	SCM2	Organisation and delivery of support	The appointment of a "designated leadership team" to organise and oversee effective care for the MHLD patient (para 1.2.1 of draft recommendations) and a "key worker" to coordinate treatment and care (para 1.2.7). If the roles as detailed are followed, it will ensure that that the "disconnect" of services (e.g. social and healthcare) currently experienced by many are avoided and that professionals, carers and service users are all properly consulted and informed both in terms of swift diagnosis and ongoing care/support.		
08	SCM2	Involving family members, carers and care workers	The general recognition that MHLD is often masked (and therefore missed!) by the overlying disability (Downs, Autism etc) is an important theme on the recommendations. The		

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
			training requirements specified for healthcare professionals in terms of identifying possible MHLD occurrences and providing ongoing care / support is therefore a vital aspect of the guideline (as is the inclusion in the already required "GP annual health check" for people with LD of consideration of mental health issues; currently rarely, if ever, considered – para 1.7).		
09	SCM2	Organisation and delivery of support	Para 1.2.5 states that "For people with learning disabilities who need inpatient treatment for a severe mental health problem, provide treatment within a locally available service and with staff who are skilled and knowledgeable in the care and treatment of mental health problems in people with learning disabilities". This is vital issue for Carers		

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
			and service users and should stop the dreadful practice of placing vulnerable MHLD patients in remote units (out of county etc).		
10	NHSE	Training for (i) Clinicians (in generic and specialist skills) related to mental health issues for CYP with learning disabilities and autistic spectrum disorder; (ii) supervisors and managers in supervision, service change and development	To ensure all professionals working with CYP in these clinical groups with mental health problems have the skills and training To identify those at risks To intervene/refer as appropriate in a timely manner. Without such an increase in capacity and skills of workforce we do not believe the goals of quality standards in particular with respect To mental health would be achievable. -The quality standard would benefit from including more specific guidance about the skills or training required by professionals and services to deliver these standards. In particular for mental health,		

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
			without clearer guidance on how these standards should be delivered, there is a risk that the full potential impact of this standard will not be realised. -NHS England has worked with Health Education England (HEE) and has developed the CYP IAPT National Curriculum for Evidence Based Psychological Therapies for Children and Young People with an Autism Spectrum Disorder and / or Learning Disability. This is a framework for a competency-based diploma-level educational programme for professional working with these groups. Significant financial, management and staff resources will be needed to make this draft quality standard achievable by local services. It is therefore		

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
			crucial to work in line with the existing Children and Young People Improving Access to Psychological Therapies (CYP IAPT) programme. The programme does not create standalone services, but works to embed the principles of evidence based practice, user participation, outcome monitoring, self-referral and training of supervisors and managers in supervision, service change and development, into existing services providing mental health care to children and young people.		
11	NHSE	Access to mainstream mental health services for people with learning disabilities	'Building the Right Support' refers to access to mainstream mental health services for people with learning disabilities. The report on Access to Mental Health beds from RCPsych makes reference to		

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
			this but identifies concerns about capacity and expertise in mainstream services DH Policy supports access to mainstream services as part of the inclusion agenda for people with learning disabilities.		
1.3 Involving people with learning disabilities, and their family members, carers or care workers, in mental health assessment and treatment					
12	The National Association of Independent Schools & Non-Maintained Special Schools (NASS)	The incorporation of the views of CYP with SEND and mental health issues into their service design and delivery.	The difficulties some CYP with SEN have in communicating, together with the inexperience of many CAMHS professional have in engaging those with SEND, means that frequently the duty to incorporate the views and wishes of the CYP into their mental health service design may be bypassed.	NASS would like to see the ACE-V quality standards (which emphasise making CYP's involvement in service design and delivery) made a key measure of service quality.	
13	Betsi Cadwaradr University Health Board (BCUHB)	Easy read/accessible information regarding mental health conditions, health promotion and the Mental Health Act.	Prevention of mental health conditions and psycho-social education will reduce strain on services and empower individuals to self manage their mental health.	There are information leaflets available, but these are of variable quality. It would be beneficial for there to be a range of standardised, quality and	Feeling Down Improving the mental health of people with learning disabilities (2014) found that 100% of people with learning disabilities surveyed said they had no written information in easy read and they felt that the information and advice was not accessible.

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
				approved easy read/accessible information leaflets for people with learning disabilities would be beneficial in health promotion. BCUHB have made their own easy read Mental Health Act leaflets and health promotion literature which have been through several stages of ratification which have proved to be extremely helpful not only for people with learning disabilities, but also for many without.	
14	SCM2	Involving family members, carers and care workers	The general theme throughout the recommendations of close and ongoing consultation with Carers/family is a vital "cog" recognising that, in many cases, it is the family or carer who detect decline in mental health in the first		

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
			instance and will provide the day to day pharmacological and psychological support post diagnosis. Experience in the past has been that diagnosis has been slow (or missed altogether) when based on "one off" healthcare consultations rather than monitoring regression in behaviour (which is mostly likely first noted by carer or family)		
1.4 Support and interventions for family members and carers					
15	SCM3	Direct support interventions to improve the psychological well-being of parents of children and adults with learning disability and mental health problems	Parents caring for children and adults with learning disability are at increased risk for mental health problems and elevated stress themselves. The presence of mental health problems in the child or adult is one of the strongest predictors of parents' psychological problems. In turn, poor parental psychological well-being is associated with poorer development and other outcomes (including	Difficulties obtaining support as a carer, and lack of recognition in services that family carer well-being is also important for the health of individuals with LD themselves.	Unknown, although data on carer assessments must be available. This is not quite what I am arguing for though.

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
			mental health problems) in children and adults with LD.		
16	SCM2	Support and interventions for family members and carers	The "support and interventions for family members and carers" laid out in para 4.1 is most welcome and should be highlighted.		
1.6 Assessment					
17	Mencap	Assessment measures	Assessment measures are not well developed		Assessment measures to detect mental health problems in people with a learning disability are not always well developed. Even if an individual is identified as having a learning disability, clinicians can face considerable problems diagnosing mental health problems. Many people with a learning disability are not able to express their feelings easily in words, which can mask the clinical presentation of a mental health problem and cause difficulty in making an accurate diagnosis (Department of Health, 2009, Page 3). This is especially a concern for people with more severe learning disabilities and people with communication problems.
18	Mencap	Diagnostic overshadowing	There is diagnostic overshadowing – this can mean people don't get the treatment they need		In this context, diagnostic overshadowing is where symptoms presented by someone with a learning disability are attributed to their learning disability rather than the true underlying problem (Mason & Scior, 2004). This can mean that mental health problems become less obvious. Mason and Scior (2004, page 86) give two reasons why this might happen: - There can be tendency to attribute behaviour to the most

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
					notable factors, which in this case is a learning disability - Clinicians may consider emotional problems to be less important when considered next to a learning disability, so effectively ignore it.
19	Mencap	Challenging behaviour as a 'catch all' diagnosis	'Challenging behaviour' as a catch all label that may mask other issues		Staff supporting people with a learning disability 'are likely to use challenging behaviour rather than a mental health framework to understand problematic behaviours' (Taylor et al., 2008, page 5). Williams and Heslop (2005) write that the concept of 'challenging behaviour' undercuts issues to do with mental health and people with a learning disability.
20	Calderstones Partnership NHS Foundation Trust		Diagnosis – How well do mental health diagnostic categories apply in learning disability, and what evidence supports this? Diagnostic overshadowing - How much are mental health problems attributable to physical health problems, and vice versa Evidence base- Lack of evidence based for treatments of mental health disorders in Learning Disability. Accessibility- For both		

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
			primary and secondary care, accessibility in terms of being seen as appropriate to mental health services, and for there to be treatment modalities adapted to the needs of people with a Learning Disability (easy read support, disability support adaptations) Capacity- Understanding the interplay between the role of mental health based capacity issues and learning disability based capacity issues in practice Risk Management- Risk assessment frameworks developed specifically for Learning Disability, for example covering assessment of depression and risk of suicide.		
21	SCM1	Understanding what is 'normal' for the individual as part of mental health assessment	In order to see differences in a persons presentation and functioning it is imperative to understand their pre-morbid functioning. Hospital		

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
			passports, all about me books and health action plans allow us to see what is normal for the person and so to assess the differences in presentation. Understanding what is usual for the person is a key recommendation in the NICE LD/MH guidance Person centred care is central to LD practice. As more and more services are expected to maximise their access to people with a learning disability it is important that assessment takes into account what is usual for a person so as to be mindful of diagnostic overshadowing. Clinically this is often how people appear to be in crisis from 'nowhere' as the early warning signs have been missed		
1.7 Annual health checks					
22	SCM3	Including a mental health element in annual health	See draft NICE guideline – mental health problems in adults with LD often missed	Increased risk and potentially severity for mental health problems	Health checks for adults with LD already exist and

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
		checks for adults with learning disability	due to processes such as diagnostic over-shadowing (see draft NICE guideline)	in adults with LD. Problems accessing mental health support.	
23	SCM3	Extend annual health checks (including mental health assessment) to children with learning disability	See above and draft NICE guideline	Only a minority of children with LD and likely mental health problems receive support for their mental health, and similar problems have been found for children with autism who also have a LD Toms, G., Totsika, V., Hastings, R. P., & Healy, H. (2015). Access to services by children with intellectual disability and mental health problems: Population-based evidence from the UK. Journal of Intellectual and Developmental Disabilities, 40, 239-247. Salomone, E., Kutlu, B., Derbyshire, K., McCloy, C., Hastings, R. P., Howlin, P., & Charman, T. (2014).	Annual health checks are already in place for adults with LD and potentially for adolescents with LD. The Education Health and Social Care Plan process in England could dovetail well with an annual health check for all children with an EHCP.

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
				Emotional and behavioral problems in children and young people with Autism Spectrum Disorder in specialist autism schools. Research in Autism Spectrum Disorders, 8, 661-668.	
24	SCM1	Annual healthcheck	There is evidence that annual health checks can directly impact on life expectancy and mortality rates. Annual healthchecks to include mental health checks are recommended in the NICE Guidance for Mental Health and LD The data and analysis from improving health and lives demonstrates that there is a very poor uptake of annual health checks nationally and that the quality of these checks varies. Annual health checks whilst encouraged are not mandated.		

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
			There is often confusion around who needs to undertake the health check. The GP's don't have capacity to undertake the whole tool but actually much of a health check could be completed prior to the GP/ Practice nurse seeing the person if the tool is accessible and clear. There is a view that health checks are just a health tool when actually they should be used to develop health action plans and care plans which make this an integrated well being tool to enable people to meet their full potential. Please see IHAL data, 6 lives report, CIPOLD report for additional information. Also, mortality review		
1.8 Psychological interventions					
25	Challenging Behaviour Foundation		1.8.9 Parental Training Programmes	Like the CBLD guideline there is reference to the evidence that behavioural	Knowledge drawn from behavioural research clearly indicates the potential benefits of providing evidence-based behavioural interventions and of doing so early. There is

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
				parent training might be helpful in reducing behavioural and emotional problems (i.e., "mental health problems") in children with LD. Thus there is a recommendation related to this evidence. However, there is another reason why one might want to recommend these interventions. Nearly all the studies also measure parental well-being/psychological problems/mental health as outcomes too. The evidence suggests that parental well-being also benefits. Thus, these sorts of interventions could be also potentially recommended in the context of reducing distress for family members who support a child with LD who has mental health problems.	robust evidence that early behavioural interventions can have positive effects on both parent and child outcomes and NICE guidelines (2013, Antisocial behaviour and Conduct Disorder in Children and Young people: The NICE guidance on recognition, intervention and management) recommend parental training. The Government has acted on this evidence through the roll out of CANPARENT parenting classes. Systematic reviews of evidence-based parenting programmes (in particular the Triple P and Incredible Years interventions) have shown the effects to be improved parenting skills, improved parental well-being and reduced behavioural problems among children. Barlow, J., Smailagic., N., Bennett, C., Huband, N., Jones, H., & Coren, E. (2011). Individual and group based parenting programmes for improving psychosocial outcomes for teenage parents and their children. Cochrane Database of Systematic Reviews, Issue 3. Art. No.: CD002964. DOI: 10.1002/14651858.CD002964.pub2

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				This is the strongest evidence currently there is for interventions that could be supportive for parents as well as the child.	
26	Challenging Behaviour Foundation		1.8.9 Parental Training Programmes	The CBF offers Positive Behavioural Training, which is co-produced, and co delivered by professional and families. This training provides an opportunity to work in a person centred way around the needs of an individual with all the people who are involved in supporting them. This reinforces the vital role of partnership working between families and professionals. See http://www.challengingbehaviour.org.uk/training-consultancy/cbf-training/training.html	Formal evaluations of CBF workshops found statistically significant benefits for both adults and children following the workshops: · Reductions in the perceived frequency, severity and management difficulty of challenging behaviours · Improvements in the emotional wellbeing of family carers and teaching staff • Increased understanding about the causes of challenging behaviour Other outcomes included: • Parents gained new knowledge • Parents gained strategies from the Workshops • Saw changes in behaviour • Highlighted improved family life • Parents feeling better • Enhanced Relationships with School
27	Betsi Cadwaradr University	Use of social/psychological interventions	There is mounting evidence for the effectiveness of psychological therapies for	With ever reducing budgets psychology resource (not only for	There is growing evidence of the effectiveness of psychotherapy and counselling for people with learning disabilities (Hollins, 2003). In a retrospective case notes review

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	Health Board (BCUHB)		people with learning disabilities (Taylor et al, 2013).	people with learning disabilities, but the general public as a whole) are being stretched. In the case of community based learning disability psychology this can mean more time being involved in assessments impacting on the time for therapeutic interventions.	of anonymised data relating to 100 sequential patient episodes, (Parkes et al 2007) found that a total of 81 people of 100 with a range of intellectual disabilities from mild to severe were assessed as suitable for therapy; 66 were eligible for individual, art or group therapy.
1.9 Pharmacological interventions					
28	Living with Harmony		Proactive support for mental health including focusing on meaningful activity and peer support. The use of non-drug interventions as the 1st choice for support. The ability for people with an LD to work in partnership to manage medication can be dangerously limited. Carers may not be competent or confident to advocate. Medication should be regularly reviewed and the		

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			needs of the person and the benefits to them should be central. Support for carers should be given quickly to ensure that they are able to manage changes in mental health of the person they care for. This should include peers support for carers and fast track assessments.		
29	SCM1	Review of Mental Health Medications	Many people with a learning disability are taking multiple psychotropic medications. The LD census data showed that 72% of people in inpatient provision were prescribed regular anti-psychotic medications. Recent reports show that there is still ongoing high usage of mental health medications in people with a learning disability. Some of these cases will appropriate in that the person has a mental illness requiring		

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			treatment but many are being medicated purely due to having a learning disability, Many of these patients will be on these medications at high doses for many years without clear rationale and evidence base for what prescribing them to the individual is trying to achieve Please see Chris Hatton's analysis of HSCIC data, medication prescription information in the LD census, Royal College of Psychiatry 2016 (FR/ID/09) guidance re prescribing and LD.		
1.11 Occupational interventions					
30	Betsi Cadwaradr University Health Board (BCUHB)	Strengthening the role of local community learning disability services in providing quality primary care	With the proposed closure of up to half of long stay NHS hospital beds for people with learning disabilities and cultural change to community support, local community learning disability services will have to adapt, expand and	Joint Commissioning Panel for Mental Health (2012) state 'that Mental health problems should be managed mainly in primary care by the primary health care team working collaboratively with other services, with	The Mental Health (Welsh) Measure (2010) states that the services that it is expected will be delivered within local primary mental health support services are: a) comprehensive mental health assessments for individuals who have first been seen by a GP, and for whom the GP considers a more detailed assessment is required, or who are referred through secondary mental health services (where the local joint scheme provides that individuals in receipt of secondary mental health services are eligible);

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			strengthen their support around primary care to minimise the risk of relapse and/or people going into crisis.	access to specialist expertise and to a range of secondary care services as required.'	b) short-term interventions (i.e. treatment), either individually or through group work, if the initial assessment has identified this as appropriate. Such interventions may include counselling, a range of psychological interventions including cognitive behavioural therapy, solution-focussed therapy, family work, online support, stress management, bibliotherapy and education; c) onward referral and the co-ordination of next steps with secondary mental health services, where this is felt to be appropriate for an individual; d) provision of support and advice to GPs and other primary care providers (such as practice nurses) to enable them to safely manage and care for people with mental health problems; e) provision of information and advice to individuals and their carers about interventions and care, including the options available to them, as well as 'signposting' to other sources of support (such as support provided by third sector organisations), and helping them to access these services.
Additional areas					
31	Action on Hearing Loss	General	Action on Hearing Loss is the charity formerly known as RNID. Our vision is of a world where deafness, hearing loss and tinnitus do not limit or label people and where people value and look after		

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			their hearing. We help people confronting deafness, tinnitus and hearing loss to live the life they choose. We enable them to take control of their lives and remove the barriers in their way. We give people support and care; develop technology and treatments and campaign for equality. Some people with severe or profound levels of hearing loss use British Sign Language (BSL) as their main language and may require specialist care and support. The commissioning of mental health and adult social care services does not always take account of the unique communication needs of people who use BSL. Our response will focus on key issues that relate to people with hearing loss. Throughout this response we		

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			use the term 'people with hearing loss' to refer to people with all levels of hearing loss, including people who are profoundly deaf who may use British Sign Language (BSL). We are happy for the details of this response to be made public. Action on Hearing Loss supports the broad aims of this quality standard to improve the prevention, assessment and management of mental health problems in people with learning disabilities. Diagnosing and managing hearing loss, and taking hearing loss into account when diagnosing and managing mental health problems is crucial for good communication and care. Evidence suggests around 40% of people with learning disabilities also have hearing loss and this often		

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			undiagnosed or misdiagnosed[1]. People with hearing loss have an increased risk of mental health problems and there is good evidence that hearing aids reduce these risks. Without hearing aids, people with hearing loss will struggle to communicate with friends, family and health and social care professionals and will be at greater risk of worse care and poor health. Evidence suggests people with learning disabilities are more likely to develop hearing loss earlier compared to the general population and are also less likely to report hearing loss due to communication difficulties[2]. Some people with severe or profound levels of hearing loss use British Sign		

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			Language (BSL) as their main language and may require specialist care and support. The commissioning of mental health and adult social care services does not always take account of the unique communication needs of people who use BSL. Below, we set out five key areas which would improve the diagnosis and management of mental health problems in people with learning disabilities.		
32	Action on Hearing Loss	1. Awareness of the growing prevalence and impact of hearing loss and links between hearing loss and mental health.	There are 11 million people with hearing loss, about one in six of the population[3]. Hearing loss is caused by a number of factors which could include regular and prolonged exposure to loud sounds, ototoxic drugs, genetic predisposition or complications from injuries or other health conditions. Age related damage to the cochlear is the single biggest	There is good evidence that hearing aids improve the quality of life for people with hearing loss, and reduce the risk of mental health problems such as anxiety and depression, however many people are waiting too long to get their hearing tested. Evidence suggests that people wait on average ten years	Our Hearing Matters report provides up to date evidence on the prevalence and impact of hearing loss across the UK. For more information, please visit www.actiononhearingloss.org.uk/hearingmatters Our Joining up report provides further information on the relationship between hearing loss and other long term health conditions such dementia, stroke and cardiovascular disease. The report found that at least £28 million could be saved every year by properly managing hearing loss in people with dementia. For more information, please visit www.actiononhearingloss.org.uk/joiningup

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			cause of hearing loss. Over 70% of people over 70[4] have hearing loss and due to the ageing population, the number of people with hearing loss is set to grow in the years to come. By 2035, we estimate there will be approximately 15.6 million with hearing loss. There are also an estimated 900,000 people in the UK with severe or profound hearing loss. Some people with severe or profound hearing loss may use British Sign Language (BSL) as their main language and may consider themselves part of the Deaf Community, with a shared history language and culture. Based on the 2011 census, we estimate that there are at least 24,000 people across the UK who use BSL as their main language – although this is likely to be an	before seeking help for their hearing loss and when they do, GPs fail to refer 45% of people reporting hearing loss to hearing services[17] There are currently no national screening programmes for hearing loss, including for people with learning disabilities. People with learning disabilities are more likely than the general population to experience hearing loss and may need additional support to get the most out of their hearing aids[18]. For more information and a full list of references, please see key area for quality improvement 2.	Hearing loss and learning disability Foundation for people with learning disabilities, 2015. Hearing Loss. Available from: http://www.learningdisabilities.org.uk/help-information/learning-disability-a-z/h/hearing-loss/ Kiani R and Miller H (2010) Sensory impairment and intellectual disability Advances in psychiatric treatment. 16, 228–235; Timehin, C. and Timehin, E (2004) Prevalence of hearing impairment in a community population of adults with learning disability: access to audiology and impact on behaviour. British Journal of learning disabilities, 32 (3), 128-132. The impact of hearing loss on quality of life Chisholm et al (2007) A systematic review of health-related quality of life and hearing aids: Final report of the American Academy of Audiology task force on the health-related quality of life benefits of amplification in adults. Journal of American Academy of Audiology, 18, 151-183. Hearing loss and other health conditions Gurgel et al (2014) Relationship of Hearing Loss and Dementia: A Prospective, Population-Based Study. Otology & Neurotology. 35 (5), 775-781. Lin FR et al. (2011) 'Hearing loss and incident dementia'. Archives of Neurology, 68 (2), 214-220. Monzani et al (2008) Psychological and social behaviour of working adults with mild or moderate hearing loss'. Acta

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			underestimate[5]. A significant body of evidence shows that hearing loss is a serious condition that can have an adverse impact on a person's health and quality of life[6]. Hearing loss has been shown to have a negative impact on overall health. Studies have found that hearing loss is independently associated with increased use of health services, an increased burden of disease amongst adults and an increased risk of mortality[7]. Hearing loss has also been associated with more frequent falls[8], diabetes[9], stroke[10] and sight loss[11]. Evidence suggests people with learning disabilities are more likely to develop hearing loss earlier compared to the general population and are also at		Otorhinolaryngologica Italica, 28 (2), 61-6. Hearing loss and mental health problems Eastwood et al (1985) Acquired hearing loss and psychiatric illness: an estimate of prevalence and co-morbidity in a geriatric setting. British Journal of Psychiatry, 147, 552–556. Monzani et al (2008) Psychological profile and social behaviour of working adults with mild or moderate hearing loss. Acta Otorhinolaryngologica Italica, 28 (2), 61–66. Saito et al (2010) Hearing handicap predicts the development of depressive symptoms after three years in older community-dwelling Japanese. Journal of the American Geriatrics Society, 58 (1), 93-7. Hearing loss diagnosis and treatment Davis et al (2007) Acceptability, benefit and costs of early screening for hearing disability: A study of potential screening tests and models. Health Technology Assessment, 11, 1–294.

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			greater risk of associated health problems[12]. Research shows that people with hearing loss may find it difficult to communicate with other people and this may lead to feelings of loneliness, emotional distress and withdrawal from social situations . Hearing loss has been shown to have a negative impact on overall health. People with hearing loss are more likely to develop paranoia, anxiety and other mental health issues – for example, evidence shows that hearing loss doubles the risk of developing depression . There is strong evidence of link between hearing loss and dementia. . Research shows that hearing loss can also be misdiagnosed as		

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			dementia or make the symptoms of dementia appear worse . Given the high prevalence of hearing loss in people with learning disabilities, and the association between hearing loss and other health conditions, health and social staff in leadership roles must consider the different forms of support people with hearing loss may need when planning and commissioning services. For more information, please see key areas for quality improvement 2, 3 and 4.		
33	Action on Hearing Loss	2. Awareness of importance of early diagnosis and treatment	Without hearing aids people with learning disabilities may find it even more difficult to communicate with friends, family and health and social care professionals. There is good evidence that hearing aids help people communicate well, improve quality of life and reduce	Hearing aids improve quality of life[22] and help people with hearing loss communicate, stay socially active and reduce the risk of loneliness and depression[23]. New evidence suggests they may even reduce the risk of dementia[24].	The benefits of hearing aids Chisholm et al (2007) A systematic review of health-related quality of life and hearing aids: Final report of the American Academy of Audiology task force on the health-related quality of life benefits of amplification in adults. Journal of American Academy of Audiology, 18, 151-183. Mulrow et al (1992) Sustained benefits of hearing aids. Journal of Speech and Hearing Research, 35 (6), 1402-5. Hearing loss diagnosis and treatment

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			mental health risks, but many people are waiting too long to get their hearing tested. People with learning disabilities in particular may struggle to report their hearing loss due to communication difficulties[19]. Around 40% of people with learning disabilities have some level of hearing loss, which is higher than the general population and people with learning disabilities are more likely to develop hearing loss earlier compared to the general population[20]. In line with NICE's quality standard for the mental wellbeing of older people in care homes[21] health and social care staff should be alert to the early signs of hearing loss and also be aware of the GP referral pathway for assessment and treatment.	However, many people are waiting too long to get their hearing tested. Research shows that people wait on average ten years before seeking help for their hearing loss and hearing aids are most effective when fitted early[25]. Evidence suggests that people with learning disabilities may need additional support to get the most out of their hearing aids. Around 70% of people with learning disabilities have been seen by an audiologist, but only 24% receive on-going assessments and hearing aid maintenance[26] Every person with learning disabilities, and everyone who needs hearing aids should get on-going adjustments and support	Davis et al (2007) Acceptability, benefit and costs of early screening for hearing disability: A study of potential screening tests and models. Health Technology Assessment, 11, 1–294. Timehin and Timehin (2004) Prevalence of hearing impairment in a community population of adults with learning disability: access to audiology and impact on behaviour. British Journal of learning disabilities, 32 (3), 128-132. Related NICE Quality Standards NICE (2013) Mental wellbeing of older people in care homes. QS50

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				– these are proven to increase hearing aid use and improve communication.	
34	Action on Hearing Loss	3. Improving the accessibility of health and social care services	People with learning disabilities may need additional support to communicate well during appointments due to their hearing loss. Failure to provide communication support can lead to confusion over diagnosis and ineffective care. When contacting services, people with hearing loss may find it difficult or impossible to use the telephone and may benefit from alternative contact options such as email, SMS text, text relay or BSL video relay services. In the consultation room people who wear hearing aids may benefit from technology such as electronic hearing loop systems that	Research shows that people with hearing loss may find it difficult to contact health and social care services when they need to and may struggle to understand what is being said in the consultation room due to poor deaf awareness or the lack of communication support. Our Access All Areas[27] research shows after attending an appointment with their GP, more than a quarter of survey respondents (28%) had been unclear about their diagnosis and approximately a fifth (19%) had been unclear about their medication. When asked why they felt	Our Access All Areas report provides evidence of the experience of people with hearing loss when accessing primary care services. www.actiononhearingloss.org.uk/accessallareas Our Caring for Older People with Hearing Loss nursing practice toolkit provides practical guidance on making services accessible for people with hearing loss. The project aimed to test out changes to hospital setting that could improve the care of older people in hospital and many of the recommendations are relevant for other healthcare settings. The project found that simple steps such as hearing screening, staff training and the provision hearing aid maintenance kits and listening equipment on hospital wards improved the care of older people in hospital. For more information, please visit www.actiononhearingloss.org.uk/nursingtoolkit We have also produced guidance for GP on improving accessibility for people with hearing loss https://www.actiononhearingloss.org.uk/supporting-you/when-you-need-to-see-a-gp/guidance-for-gps.aspx The full specification and implementation guidance for NHS England's Accessible Information Standard can be found at

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			improve speech clarity by reducing the level of background noise. People who use BSL may need support from communication professional to help them communicate well and understand written information, such as BSL interpreter. Staff involved mental health assessment and treatment of people with learning disabilities should meet the requirements of NHS England's Accessible Information Standard, which provides clear guidance on what all providers of NHS and adult social care must do to make their services accessible for people with sensory loss and learning disabilities, including people with hearing loss. The standard establishes a clear framework to make sure people can communicate	unclear after their appointment, more than half (64%) said the GP did not face them and more than half (57%) said the GP did not always speak clearly – suggesting that if GPs followed simple communication tips, this could improve understanding and make treatment more effective. People with hearing aids may also benefit from hearing loop systems, yet over a third (35%) said these weren't available. The situation is even worse for people who use BSL. Research by the Our Health in Your Hands campaign[28] shows more than two thirds (68%) of survey respondents who asked for a sign language interpreter for their GP appointment didn't get	www.england.nhs.uk/accessibleinfo

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			well during appointment and receive information in a format they can understand.	one and more than two fifths (41%) felt unclear about their diagnosis because they couldn't understand the sign language interpreter. Research by the charity Signhealth[29] also suggests that people who use BSL are at risk of poor health due to inaccessible public health information. Over a third (34%) of people who use BSL who had a health assessment were unaware they had high or very high blood pressure, and of those who had already had a diagnosis of hypertension, around two thirds (62%) had high blood pressure compared to a fifth (20%) of the general population.	
35	Action on Hearing Loss	4. Improving the availability of specialist mental health and adult social care services for people who use BSL	People with learning disabilities who use BSL may need specialist mental health and adult social care services that take account of the	Across the UK, only three mental health trusts and four local community mental health teams provide specialist services	Mental health services for people who use BSL NHS England's service specification for specialist mental health services for people who use BSL provides more information on commissioning mental services for people who use BSL. For more information, please visit

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			unique language and culture of the Deaf community. A systematic review[30] of the literature on mental health and deafness shows that people who have severe or profoundly levels of hearing loss have an increased risk of mental health problems. Standard tests and mental health measures may be ineffective if people with who use BSL are unable to communicate well in English. The review also shows that people who use BSL value specialist mental health services that use medically skilled BSL interpreters. People with learning disabilities who use BSL may also need culturally sensitive adult social care and support. This includes the provision of a qualified BSL interpreter and also support to help people who use BSL communicate well and	for people who use BSL[31]. The low number of mental health services suggests the mental health needs of people who use BSL are going unmet.	https://www.england.nhs.uk/commissioning/wp-content/uploads/sites/12/2013/06/c04-deaf-mh.pdf Department of Health (2005) Mental health and deafness; towards equity and access. Fellinger et all (2012) Mental health of deaf people. The Lancet, 379 (9820), 1037-1044. Adult social care services for people who use BSL We have developed person centred thinking and service planning tools to help people who use BSL have choice and control over how their care is provided. For more information, please visit https://www.actiononhearingloss.org.uk/supporting-you/care-and-support/person-centred-working/person-centred-tools.aspx The Making it Real standards also set out what people who use services should expect and when accessing adult social care. For more information on good practice for people with sensory loss, please visit http://www.thinklocalactpersonal.org.uk/_library/MakingItReal/MIRSensoryLoss-online-pdf_002.pdf

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			participate in local community, for example by supporting people to attend local Deaf clubs or other community groups. When arranging adult social care for people with learning disabilities who use BSL, health and social care practitioners should use specialist planning tools to make sure people who use BSL have choice and control over how their care is provided. Evidence suggests that the commissioning of mental health and social care does not always take account of the unique needs of people who use BSL. More needs to done to make sure people with learning disabilities who use BSL can access the specialist services they need.		
36	The National Autistic Society	Autism – general inclusion	As a general point, we would like to express some concern that autism is not yet		

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			included in the draft scope of this Quality Standard. Autistic people are currently at greater risk of developing mental health problems, alongside people with a learning disability. Some people will have both (studies suggest between 20% and 33% adults known to social services with a learning disability also have autism). Autistic people will need mental health support to be adapted (this is expanded on below). We believe it is vital that NICE expand this Quality Standard to specifically include autistic people (those who also have a learning disability and those who have no learning disability).		
37	The National Autistic Society	Autism and Transforming Care	We welcome NICE's work to create a new Quality Standard that will support practice under NHS England's important Transforming Care programme. However, we	The 2015 Learning Disability Census found that, of those covered receiving inpatient care and treatment, 39% in total had a diagnosis of	We suggest that the following also be included in key development sources: - NHS England (2015) Supporting people with a learning disability and/or autism who display behaviour that challenges, including those with a mental health condition

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			are concerned that, as currently drafted, the population to be covered (as at para 3.1) does not match that of Transforming Care as it does not include people on the autism spectrum.	autism, while 15% had a diagnosis of autism without a learning disability. There are therefore a significant number of relevant people in inpatient units who would not be covered by this Quality Standard and will not benefit from improved quality. We note that many of the key development sources listed in the draft scope also cover autism. NICE should therefore take this opportunity to include autism in the scope and apply the important learnings contained within these documents.	We recommend that the NICE Quality Standard on autism [QS51] be included at para 3.3.
38	The National Autistic Society	Autism and access to mental health services	The Government's Mandate to NHS England clearly cites autism as an area where health inequality (including mental health) must be reduced.	Although autism is not a mental health condition: - 70% autistic children develop mental health problems. As many as 1 in 10 children who use Child	Adaptations to mental health interventions are referenced in NICE Guidelines Autism in adults: diagnosis and management [CG142] at para 1.6, and Autism in under 19s: support and management at para 1.7 and should be incorporated in this Quality Standard to ensure use.

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			If an autistic person develops a mental health problem, they need appropriate therapies from appropriately trained professionals. Conventional therapies, unadapted, may be inappropriate in dealing with their mental health problems and can lead to them needing more intensive interventions. In its mandate to Health Education England (HEE), the Department of Health recognised the importance of ensuring that training in autism was included in medical training programmes.	and Adolescent Mental Health Services. - 16 – 35% of autistic adults have a comorbid psychiatric disorder. Despite the high prevalence of mental illness, the experience people with autism have of mental health services, both in the community and in in-patient facilities, is often poor. Children and adults with autism should expect to be supported by mental health services which are knowledgeable about autism, are able to provide speedy and effective diagnosis, and are able to adjust professional practice and therapeutic interventions to meet the needs of the individual.	

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				This requires urgent improvement.	
39	The National Association of Independent Schools & Non-Maintained Special Schools (NASS)	Awareness and identification of mental health issues in children and young people with SEN.	As non-clinicians, NASS is choosing not to respond formally to the draft guidance. However, we would note overall, the discrepancy between knowledge and understanding of issues for adults with SEND compared to children and young people. Children and young people (CYP) with special educational needs and disability (SEND) can best have their mental health situation professionally observed by teachers and medical practitioners such as GPs. It is crucial that a knowledge of the frequency of mental health conditions in those with SEN and how they can manifest in a non-standard way is present in these groups. Whilst the	Most school staff have no access to relevant mental health training, and the majority admit that they are unable to spot potential mental health difficulties. Many GPs are similarly lacking in confidence. SEND training is likely to feature prominently in the new core initial teacher training scheme; and the recently published Five Year Forward View on Mental Health recommended core mental health training for all GPs by 2020. The current Mental Health Services and Schools Link Pilots – which are designed to support joined-up working between schools and health services – also	Please see page 5 of the NFER Teacher Voice Omnibus: questions for the Department for Education – June 2015 Research brief, which highlights the data regarding teacher confidence in dealing with pupils' mental health issues: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/483275/DFE-RR493_Teacher_voice_omnibus_questions_for_DfE_-_June_2015.pdf Additionally, there is still a split in education-based interventions to look at SEND and mental health in isolation and not to recognise co-morbidity. In 2012 NASS launched a Knowledge transfer Partnership funded e-learning package for schools 'Making Sense of Mental Health'. This targeted raising knowledge and awareness of mental health needs in children with learning difficulties. It has been used by over 1000 staff to date: http://www.makingsenseofmentalhealth.org.uk

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			draft guidance acknowledges the key role played by GPs, schools play an even more major role in identifying potential mental health problems. We would like to see greater links between education and health reflected in the guidance.	represent a step in the right direction. However, even if fully implemented, both professions will still have 'blind spots' with regard to CYP with both SEND and mental health issues. We believe that there is still stigma attached to 'dual diagnosis' of SEND and mental health problems that lead to mental health problems being missed or ignored.	
40	The National Association of Independent Schools & Non-Maintained Special Schools (NASS)	CAMHS services for looked after children (LAC) with SEND.	DfE statistics from 2014 indicate that 67% of LAC have SEND, and both LAC status and SEND individually and combined dramatically increase a child's chance of mental health conditions.	The Department for Education and DfE and DH guidance on promoting the health and wellbeing of LAC only states that "CCGs, local authorities and NHS England should ensure that CAMHS and other service providers targeted and dedicated support to LAC according to need". The SEN section of the guidance makes no reference to the high	

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				prevalence of mental health issues amongst those with SEN. The extent and quality of mental health services for LAC and those leaving care – particularly those with SEND – is an area of deficit and concern for schools and children's homes working with LAC.	
41	The National Association of Independent Schools & Non-Maintained Special Schools (NASS)	The provision of support for those with severe and complex mental health disorders and SEND.	Research by NHS England published in 2014 identified a lack of suitable tier 4 beds for CYP with severe and complex mental health disorders: such facilities are frequently utilised by CYP whose mental health difficulties are co-morbid with SEN via Tier 4 CAMHS Learning Disability Services.	As of 2014, an NHS review of Tier 4 CAMHS services found that there were only 92 beds in Learning Disability Services, out of a total of 1,264 Tier 4 beds. The same review identified bed shortages, staff shortages, a lack of intensive outreach services, delayed discharge and a lack of community services as major failings in the general Tier 4 system. With regards to CAMHS	Please see pages 53 and 54 of the NHS' Child and Adolescent Mental Health Services (CAMHS) Tier 4 Report for bed statistics: https://www.england.nhs.uk/wp-content/uploads/2014/07/camhs-tier-4-rep.pdf

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				Tier 4 Learning Disability Services specifically, the review stated that: “there are very few specialist learning disability in-patient units covering very large geographical areas and thus the issues regarding transitional support are similar. In addition community CAMHS Learning Disability Services are not well developed in many areas of the country at present. There is a need for further work on the role and remit of inpatient care for children and young people with learning disabilities and how this fits into the care pathway”. This is an increasing problem for the schools that NASS represents – many CYP with serious mental health problems	

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				or emerging psychosis are being managed in residential special schools. verlitsupport.	
42	Betsi Cadwaradr University Health Board (BCUHB)	Additional developmental areas of emergent practice: 1. Use of a dedicated mental health liaison nurse for learning disabilities.	The relatively new role of the mental health liaison nurse for learning disabilities champions equitable access to generic in-patient psychiatric services over 3 hospital sites promoting and facilitating reasonable adjustments which can consist of utilising accessible information, behavioural model/interventions, facilitating and co-ordinating additional support from learning disability support workers, use of person centred planning, extra monitoring and additional discharge planning, as well as acting as a link practitioner for all stakeholders ensure timely dissemination of important information and consistency in approach. Training both mental health	The annual audit on this role received numerous positive comments from psychiatric and learning disability professionals and service users. The ward manager of one of the PICU's covered by the mental health liaison nurse stated "Allison and I attended a National Association of Psychiatric Intensive Care Units (NAPICU) conference and took part in a workshop discussing how LD clients are entering (generic) adult services through no fault of their own. We listened to the narratives of other PICUs and felt that the input and understanding we have between your team (mental health liaison)	The role of the mental health liaison nurse has been audited, with its findings culminated in an annual report, including findings from questionnaires from a number of health professionals. All professionals that provided feedback stated that the role was beneficial for people with learning disabilities. Some went on to say that the role was "imperative", "crucial", "extremely useful" providing "brilliant in-put" and "offers a specialist opinion".

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			and learning disability nurses is another key area for future development.	and Tryweryn (PICU) is beyond what others are doing in the country. Other units are scratching their heads in how to deal with this. We could not identify another unit who is working in a collaborative manner as we are."	
43	Betsi Cadwaradr University Health Board (BCUHB)	Additional developmental areas of emergent practice: 1. North wales have developed 3 treatment teams for people with learning disabilities that meet the criteria for dialectical behaviour therapy (DBT). These individuals are at high risk of suicide, self harm and seriously dysregulated behaviours that pose a risk to themselves and or others.	Criteria for people with learning disability to join DBT is; • Mild/Moderate LD • On crisis pathway • Adult • High risk behaviour in past 6/12 that puts their placement/life at risk • Clear episodes of suicidal behaviour, self harm and/or extremely impulsive behaviours that interfere with functioning /threaten security of placement • +3 areas of dysregulation (emotional, interpersonal, self or cognitive - plus self impulsive behaviour)	DBT has a strong evidence base for providing effective interventions for difficult-to-treat populations such dual diagnosis, eating disorders, geriatric depression. This is a resource intensive treatment, but can have very positive clinical outcomes with life changing results. This kind of intervention supports support and treating individuals in the community and proactively engaging with service users to minimise	Improve quality of life (Brown et al, 2013; Swales, 2010, Linehan,1993) Increase IQ by 10 points (Brown et al, 2013) Little research and in-depth studies. (Merrick et al 2006) More likely to present with mood complaints, anxiety and suicidality. (Merrick et al 2006, Giannini et al 2010). Roscoe et al, 2015 suitably adapted structure to meet needs of inpatients North wales teams are collecting baseline/pre-treatment scores, mid way scores and post therapy scores to demonstrate the effectiveness of the treatment. References American Psychiatric Association. (2000). Diagnostic and statistical manual of mental disorders. 4th (ed.) DSM-IV-TR. Washington: American Psychiatric Association Brown, J. Brown, M. & Dibiasio, P. (2013). Treating individual with intellectual disabilities and challenging behaviours with adapted dialectical behaviour therapy. Journal of mental health research in intellectual disabilities, 6:280-303

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			• Be able to communicate in simple sentences an hour every week In pre treatment people; • Establish if DBT is a suitable treatment • Therapist assists the client in addressing treatment goals • Orient client to the treatment (pros and cons) • Elicit commitment There is a requirement for patients to be committed to the following; See 1:1 therapist for an hour every week Show you want to change Takes a year at least 4 hours ++++ Go to 2hours of skills training Homework + diary Practice mindfulness	relapse and promote recovery.	Giannini, M. Bergmark, B. Kreshoever, E. Elias, E. Plummer, C. & O'Keefe, E. 2010. Understanding suicide and disability through three major disabling conditions: Intellectual disability, spinal cord injury, and multiple sclerosis. Disability Health Journal. 3(2): 74-8 Linehan, M. (1993). Cognitive-behavioural treatment of borderline personality disorder. New York: The Guilford Press Linehan, M. (1993). Skills training manual for treating borderline personality disorder. London: The Guildford Press Merrik, J. Merrik, E. Lunsk, Y. & Kendal, I. (2006). A Review of Suicidality in Persons with Intellectual Disabilities J Psychiatry Rel at Sci 43. 4 258–264 Swales, M. (2010). Implementing Dialectical Behaviour Therapy: organizational pre-treatment. The Cognitive Behaviour Therapist: page 1 of 13 Swales, M. (2010). Implementing DBT: selecting, training and supervising a team. The Cognitive Behaviour Therapist 3, 77–79.
44	South West Yorkshire Partnership NHS Foundation Trust	Other Comments	Complimentary approaches will include psychological therapies such as CBT, psychodynamic psychotherapy, Dialectical Behavioural Therapy,		

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			Cognitive analytic therapy etc which are mentioned in the report but are not adequately linked. In the DoH/BILD short film explaining PBS, psychological therapies are mentioned in relation to this. There have been requests from practicing clinicians for information on these approaches for people in the Care and Treatment reviews.		
45	South West Yorkshire Partnership NHS Foundation Trust	Other Comments	The Royal College of Psychiatrists and the British Psychological Society have just published a report on psychological therapies which may also inform the NICE Guidance – titled Psychological therapies and people who have intellectual disabilities.		
46	SCM1	Additional areas- Transforming care and CTRs Health action plans	1) Quality standards around what is expected to make a CTR meaningful including rationale for hospital admission and treatment plans looking at future		

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			planning would fit with national direction of travel but also enhance quality for people using services 2) Often even if people have a healthcheck if this is not turned into a health action plan the likelihood of improvement in the persons health is limited.		
47	NHSE	Participation of children, young people (CYP) and their parents/carers in designing, planning, delivery and reviewing of services	Participation of children, young people (CYP) and their parents/carers in all decisions/plans that affect them, which includes designing, planning, delivery and reviewing of services -Participation is particularly important when delivering care for young people and vulnerable groups including children with learning disabilities. -The evidence presented in the 2015 Children and Young People Improving Access to		

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			Psychological Therapies (CYP IAPT) National Audit programme which shows that greater involvement of children, young people and their parents/carers has led to: Reduced number of days in treatment by 21%;Increased percentage of closed cases by mutual agreement by 22%;Improved planning and delivery of care and services; Improved website information about accessing the service; Better staff recruitment, retention, training and appraisal; Improved feedback loop for treatment and service delivery. -Research by The King's Fund and Department of Health (set out in 'No decision about me, without me', 2012) highlighted the value and importance of participation in health care.		

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			Effective monitoring and accountability processes must be in place to ensure the safe, meaningful and ethical participation of Children and young people. -Local health systems must be encouraged and supported to involve children and young people routinely in their work, sharing learning and good practice, if a culture of participation is to be cultivated across the NHS. Please see the Department of Health document 'Future in mind' which highlights the importance of participation: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/414024/Childrens_Mental_Health.pdf Please see NHS England		

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			document 'Delivering With and Delivering Well" which underlines the importance of participation in CYP: https://www.england.nhs.uk/wp-content/uploads/2014/12/delvr-with-delvrng-well.pdf United Nations Convention on the Rights of the Child – The standards of most relevance to the participation of service users are: • Article 12: Children and young people have the right to say what they think should happen, when adults are making decisions that affect them, and to have their opinions taken into account. • Article 13: Children and young people have the right to get and to share information, as long as the		

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			information is not damaging to them or others. • Article 17: Children and young people have the right to receive, seek and give information. • Article 23: Disabled children and young people have the right to active participation in their community. • Article 2: Requires all of the rights in the convention on the Rights of the Child to be implemented for every child, without discrimination.		
General					
48	South West Yorkshire Partnership NHS Foundation Trust	General	Throughout the document it mentions the Nice Guidelines 2015 for Challenging Behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges, but does not specifically address how they will fit with the process that is being developed in the Mental		

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			Health document.		
49	South West Yorkshire Partnership NHS Foundation Trust	General	There is a lack of recognition that people who challenge may also have mental health needs that need addressing. Refer to the definition of Positive Behavioural Support which makes clear that a PBS plan may also include "The secondary use of other complimentary, evidenced based approaches to support behaviour change at multiple levels of the system". (Gore et al, 2013, page 16).		
50	Royal College of Paediatrics and Child Health	General	Thank you for inviting the Royal College of Paediatrics and Child Health to comment on the Mental health problems in people with learning disability consultation. We have not received any responses for this consultation.		