NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

HEALTH AND SOCIAL CARE DIRECTORATE

QUALITY STANDARD CONSULTATION

SUMMARY REPORT

1 Quality standard title

Learning disabilities: mental health problems

Date of Quality Standards Advisory Committee post-consultation meeting:
6 October 2016

2 Introduction

The draft quality standard for Learning disabilities: mental health problems was made available on the NICE website for a 4-week public consultation period between 5 August and 2 September 2016. Registered stakeholders were notified by email and invited to submit consultation comments on the draft quality standard. General feedback on the quality standard and comments on individual quality statements were accepted.

Comments were received from 17 organisations, which included service providers, national organisations, professional bodies and others.

This report provides the quality standards advisory committee with a high-level summary of the consultation comments, prepared by the NICE quality standards team. It provides a basis for discussion by the committee as part of the final meeting. Where appropriate the quality standard will be refined with input from the committee.

Consultation comments that may result in changes to the quality standard have been highlighted within this report. Comments suggesting changes that are outside of the process have not been included in this summary. The types of comments typically not included are those relating to source guidance recommendations and suggestions for non-accredited source guidance, requests to broaden statements out of scope, requests to include thresholds, targets, large volumes of supporting information, general comments on the role and purpose of quality standards and requests to change NICE templates. However, the committee should read this summary alongside the full set of consultation comments, which are provided in appendices 1 and 2.

3 Questions for consultation

Stakeholders were invited to respond to the following general questions:

1. Does this draft quality standard accurately reflect the key areas for quality improvement?

2. Are local systems and structures in place to collect data for the proposed quality measures? If not, how feasible would it be to be for these to be put in place?

3. Do you have an example from practice of implementing the NICE guideline(s) that underpins this quality standard? If so, please submit your example to the NICE local practice collection on the NICE website. Examples of using NICE quality standards can also be submitted.

4. Do you think each of the statements in this draft quality standard would be achievable by local services given the net resources needed to deliver them? Please describe any resource requirements that you think would be necessary for any treatment. Please describe any potential cost savings or opportunities for disinvestment.

Stakeholders were also invited to respond to the following statement specific questions:

5. For draft quality statement 1: In line with quality statement 1of Learning disabilities: challenging behaviour Quality Standard (QS101) - could we also call this annual health check a comprehensive health assessment? Please detail your answer.

6. For draft quality statement 3: What term would you use in your setting to describe this role? Key worker? Care or case coordinator? Please detail your answer.

7. For draft quality statement 4: Can you please define the timeframe of long-term antipsychotic drugs?

4 General comments

The following is a summary of general (non-statement-specific) comments on the quality standard.

- General support for this quality standard and the quality improvement areas identified.
- Clarify in the introduction that the population covered by this quality standard includes children, young people and adults.
- Clear definition of carers needed in this quality standard. Do they include unpaid support?
- Clear definitions of the roles and responsibilities of providers are needed in this quality standard.
- Mental capacity legislation needs to be considered in this quality standard in terms of consent or best interest decision making.
- The equality impact assessment needs to refer to the NHS England's Accessible Information Standard. Also consistency on language support was raised as only some statements include this.
- Concern raised that the introduction categorises autism as a mental health problem.

Consultation comments on data collection

- Primary care services have many different providers so data collection co-ordination may be complicated. A co-ordinated approach is needed between NHS England, commissioners and service providers.

Consultation comments on resource impact

- Comments relating to resource impact were received in relation to draft statements 1, 3 and 5, and are summarised in the relevant sections below.

5 Summary of consultation feedback by draft statement

5.1 Draft statement 1

People with learning disabilities are offered an annual health check that includes a review of mental health problems.

Consultation comments

Stakeholders made the following comments in relation to draft statement 1:

- The health check could helpfully inform the development and review of the health element of the Education, Health and Care Plan for children and young people.
- This statement needs to be aligned with NHS England's standard template for annual health checks.
- As general practices have to currently opt in to annual health checks as part of the Direct Enhanced Service (DES) this offer may be limited as only approximately 50% of eligible people with learning disabilities receive health checks.
- Query raised on GPs' expertise to assess mental health during this health check as this could lead to inappropriate mental health service referrals and have significant resource implications.
- Query raised on the population for this health check. State the start age as 14 years.
- Query raised on care workers being appropriate to offer this annual health check.

- Additional areas to include within this annual health check were:-
  - an in depth review of psychotropic medications and the 'whole person' (physical and mental) with prevention of wider determinants of mental health problems
  - specific checks for conditions associated with particular syndromes
  - specific checks on recent distress or behavioural changes without an identifiable physical cause
  - review on significant life event changes such as family bereavement, accommodation and staff changes
  - an agreed and shared care plan for managing mental health problems
  - offer this health check to children and young people receiving care away from their local area
  - to include family carer involvement.
- Need for follow up offer if the health check is initially refused.
- Concern raised on ensuring this health check data is collected and shared, especially if learning disability and mental health services do not share the same clinical records.

Consultation question 5

Stakeholders made the following comments in relation to consultation question 5:

- In line with quality statement 1 of Learning disabilities: challenging behaviour Quality Standard (QS101) - could we also call this annual health check a comprehensive health assessment? Please detail your answer.
- Mixed stakeholder opinion was received. Annual health check was the preferred name to raise its profile however comprehensive health assessment was supported as it implies physical and mental health similarities and demonstrates progress from existing annual health checks.

5.2 Draft statement 2

People with learning disabilities and identified mental health needs have a mental health assessment conducted by a professional with expertise in mental health problems in people with learning disabilities.

Consultation comments

Stakeholders made the following comments in relation to draft statement 2:

- Definitional queries on this mental health assessment were:-
  - its timing and trigger
  - who would be conducting this and the specific expertise needed
  - its focus on 'identified mental health needs' which will this exclude suspected and milder mental health needs. How are these needs be initially identified?
  - what the formal assessment questionnaire entails.
- Concern raised on the feasibility of joint working between learning disability and mental health services and the pool of expertise needed.
- Concern raised on the overlap between statements 1 and 2 with a suggestion to combine.

5.3 Draft statement 3

People with learning disabilities and a serious mental illness have a key worker.

Consultation comments

Stakeholders made the following comments in relation to draft statement 3:

- Suggestion to add 'long-term mental health illness' to the statement wording.
- Serious mental illness definition needs to include people with complex learning difficulties.
- Resource impact of the key worker's responsibilities was raised.

Consultation question 6

Stakeholders made the following comments in relation to consultation question 6:

- For draft quality statement 3: What term would you use in your setting to describe this role? Key worker? Care or case coordinator? Please detail your answer.

- Mixed stakeholder opinion was received. Key worker was viewed as a residential care and education term which may create misinterpretation. Other suggestions included case holder, named worker and Care Programme Approach (CPA) co-ordinator.

5.4 Draft statement 4

People with learning disabilities who are taking antipsychotic drugs long-term and are not experiencing psychotic symptoms have their prescriptions reduced or discontinued.

Consultation comments

Stakeholders made the following comments in relation to draft statement 4:

- NHS England's campaign Stopping Over-medication of People with Learning Disabilities which focuses on psychotropic drugs and the roles and responsibilities of prescribers and carers needs aligning with this statement.
- Concern raised that the current statement wording is prescriptive by stating reduction or discontinuation in prescription.
- Concern raised on stating 'not experiencing psychotic symptoms' in the statement as this is often reliant on observations.
- For long-term antipsychotic drug use an official diagnosis of serious mental illness is needed.
- Suggestion to acknowledge that antipsychotic drugs can prevent psychotic symptoms.
- Suggestion to include inappropriate prescribing of antidepressants within this statement.
- In order to reduce antipsychotic drugs a local approach with pharmacy, community learning disabilities and carer involvement may be needed.

Consultation question 7

Stakeholders made the following comments in relation to consultation question 7:

- For draft quality statement 4: Can you please define the timeframe of long-term antipsychotic drugs?
  Mixed stakeholder opinion received:-
  - any time after 3 months as medication effects could be measured and reviewed
  - 6 months
  - the timeframe would depend on the diagnosis and presentation of the symptoms against a treatment review on effectiveness.

5.5 Draft statement 5

Health and social care provider organisations provide parent training programmes for parents and carers of children with learning disabilities.

Consultation comments

Stakeholders made the following comments in relation to draft statement 5:

- Generally supported for using a 'whole person' approach
- This statement could require additional resources but if effective it would have a longer term saving in reducing long-term mental health problems.
- Concerns raised on these parent training programmes were:-
  - what these specifically entail
  - the link between mental health problems and quality of parenting. Parental training should be offered sensitively
  - the facilities and parental commitment required to attend these sessions
  - providing generic training programmes when specialised work is needed for children with spectrum conditions or attachment difficulties
  - the evidence of the benefit of parent training proposed and which elements will make a positive difference.
  - what the treatment manual entails.
- More detail needed on the outcome quality of relationship between carer and person being cared for. This may be difficult to locally collect.

- Reference this statement to Antisocial behaviour and conduct disorders in children and young people (Quality Standard 59) for parent training programmes and Learning disabilities: challenging behaviour (Quality Standard 101)

6 Suggestions for additional statements

The following is a summary of stakeholder suggestions for additional statements.

- Psychological interventions
- Care and Treatment Review or 'Blue Light' meeting
- Physical activity and access to exercise and sport
- Joint working between learning disability services and secondary mental health teams-Green Light Toolkit (NDTi, 2013).
- Attachment-trauma population
- Hearing loss.

Appendix 1: Quality standard consultation comments table – registered stakeholders

ID	Stakeholder	Statement number	Comments[1]
1	Lancashire Care NHS Foundation Trust	General	Social care providers and Healthcare providers other than GP practices are not in a position to 'ensure' everyone with an LD is offered an annual health check given the DES (Direct Enhanced Service- Annual Healthchecks people with Learning Disability) contracting specification is an 'opt-in' process for GP practices, could only expect that they support and engage in the process. No reference to the contracting specification within 'source guidance section.' Currently no robust standard template for DES annual health checks which specifies how standard review of mental health is required. Need to be clearer on definitions of healthcare providers/primary care providers and GP providers in terms of roles and responsibilities. Need to consider transition of commissioning from NHS England to CCGs (Clinical Commissioning Groups) who uptake L3 commissioning of DES health checks locally. No reference to adherence to Mental Capacity legislation in terms of Consent/Best Interest Decision making.
2	Action on Hearing Loss	General	NHS England's Accessible Information Standard should be included as policy document relevant to this guideline. For more information on the Standard, please see comment 5.
3	Challenging Behaviour Foundation	General	The quality standards will help to raise the profile of the importance of annual health checks, mental health assessments, the role of key worker, training for family carers as well as the overuse of antipsychotic medication. These are all key areas for quality improvement and are to be welcomed. We particularly welcome the inclusion of the need for people with learning disabilities to have a mental health assessment conducted by a professional with expertise in mental health problems in people with learning disabilities in order to improve the recognition of mental health problems. It would be helpful to have an additional quality standard about people with learning disabilities having access to a range of evidence based therapies to treat their mental health problem from professionals with expertise in mental

[1]PLEASE NOTE: Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how quality standards are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its staff or its advisory committees.

ID	Stakeholder	Statement number	Comments[1]
			health problems in people with learning disabilities. It is essential for people to have access to evidence based treatment in a timely manner. It cannot be assumed that the identification of mental health needs as part of a mental health assessment (quality standard 2) would automatically lead to these needs being met with appropriate treatment and support. Family carers contacting the CBF have reported a lack of expertise in treating mental health problem in people with learning disabilities resulting in fewer treatment options (e.g. medication only) or no treatment options being offered to their relative. This is discriminatory and leads to serious consequences for the individual and their families. Escalating support needs as a result of untreated mental health needs leads to a higher cost to the public purse.
4	Public Health England Learning Disabilities Observatory	General	It is essential to be clear that everybody needing mental health services has access to them locally. Historically people with learning disabilities are sometimes not eligible for CAMHs/adult mental health services. Reasonable adjustments should be made to ensure that people with learning disabilities have access to mental health services.
5	Royal College of Paediatrics and Child Health	General	We are very concerned indeed to see autism categorised as a 'mental health problem' in this standard and believe that people with this spectrum of conditions would consider this offensive. Autism is a different way of seeing and understanding the world, a different way of being. It does bring its challenges, but it is NOT a 'mental health problem'. This must please be properly addressed in this quality standard. It would be better to refer to people with mental health conditions and/or neurodevelopmental conditions such as autism spectrum conditions' rather than lumping all together as 'mental health problems'.
6	NHS England	General	NHS England welcomes the focus on mental health problems with learning disabilities in this NICE quality standard, and while we recognise that such quality statements do not typically provide guidance with regard to training, the delivery of this particular quality standard could be enhanced by the new CYP IAPT National Curriculum for Evidence Based Psychological Therapies for Children and Young People with an Autism Spectrum Disorder and / or Learning Disability, developed by NHS England with Health Education England (HEE). This is a framework for a competency-based diploma-level educational programme for professional working with these groups. This curriculum has been designed by national experts based on relevant NICE guidance. This will ensure all LD and/or mental health professionals have the skills and training to identify those with mental health needs to intervene/refer as appropriate in a timely manner. Without such an increase in capacity and skills of workforce it will be hard to

ID	Stakeholder	Statement number	Comments[1]
			achieve the goals of the quality standards with respect to mental health. Please find embedded a copy of the national curriculum. This is DRAFT and NOT for circulation.
7	NHS England	General	Can we add to the list of outcomes from the quality standards that patient outcomes improve (could be goal-based outcomes?).
8	NHS England	General	It reads as a document addressing the need of adults – the examples cited are adult focussed. We suggest this is reframed to be either people of all ages or include children and young people explicitly.
9	Public Health England	General	Autism is not a mental health problem. People with autism may experience mental health problems as with any other group of people with different learning disabilities. The standards that have been defined are clear and appropriate with easily measurable indicators. Prevention standards are the weakest section and should be strengthened to include physical activity and access to exercise and sport. Inclusion and reasonable adjustments need to be mentioned. In respect of the indicator on wider determinants of health, employment, it is necessary to note that employment itself if not appropriately supported for people with a learning disability can be as socially iso0lating as not being employed. The list of quality statements are very good but could be strengthened with supporting lines.
10	Department of Health	General	The Department of Health has no substantive comments to make, regarding this consultation.
11	Real Life Options	General	We would like to express our support for this quality standard and feel that aspects that we have commented on previously have been incorporated.
12	Royal College of Nursing	General	The Royal College of Nursing has no comments to submit to inform on the above quality standard consultation at this time.
13	NHS England	EQIA	Equality and diversity - some sections include a language requirement and others (e.g. p27) don't.
14	Challenging Behaviour Foundation	Introduction	It would be helpful to say "children, young people and adults" instead of "people" in the introduction so it is clear that the quality standard also applies to children with mental health problems and learning disabilities. Early intervention is vital and it is important that these standards are not overlooked for children because of a

ID	Stakeholder	Statement number	Comments[1]
			misunderstanding over the scope. In our experience "people" is perceived to mean adults. It is also important that it is made clear that the quality standards apply to children and young people in the publicity that accompanies the quality standards
15	Royal College of Paediatrics and Child Health	Introduction	In the outcome measures box, outcome 1E is only meaningful if it is expressed as a proportion of adults with Learning Disability (LD) who have the capacity to work, rather than a blanket % of all with LD who are employed, as for those who are totally dependent for all care and have the most severe learning disabilities employment would not be possible or appropriate.
16	British Psychological Society	Introduction	The Society has concerns that the document uses the term Mental Health, throughout and believes that it would be more appropriate to consider Emotional Wellbeing and Mental Health, as they are on a continuum and Learning Disability (LD) services are not the same as mental health teams. Therefore some Emotional Wellbeing/Mental Health work is undertaken in LD services, but not all. We also believe that the term serious mental health problem should be used, rather than 'illness' (e.g. page 23) to avoid a dichotomy between people who are 'well' and 'unwell'. There also seemed to be a lack of emphasis throughout the quality standard on joint working between LD services and secondary mental health teams. We often feel that the best support to people with LD with mental health problems occurs through joint working, as advocated and measured through the Green Light Toolkit (NDTi, 2013).
17	British Psychological Society	Introduction	The Society believes that it would be helpful to reference the emerging understanding that adults with Learning Disabilities also experience Attachment-trauma disorders. Given the high rates of childhood abuse and neglect in this population, we feel that it is vital that we recognise this pattern. PTSD does not best describe these issues. Instead, this makes reference to the specific neurodevelopmental impact that occurs with childhood neglect. The individual who made this comment stated that the vast majority of their caseload (psychology) have experienced significant attachment trauma which impacts on every relationship in adult life, future mental health needs, sensory development, cognitive presentation, social and physiological development.
18	British Psychological Society	Introduction	We believe that it is potentially unhelpful / inaccurate to describe autism in particular, but also dementia, ADHD, and pica as 'mental health problems' per se.
19	British Psychological Society	Introduction	Some mental health support is offered from LD services so this is potentially misleading / potentially would miss capturing information about those who access mental health support from LD services, by only referring to

ID	Stakeholder	Statement number	Comments[1]
			'secondary mental health teams' in these outcome measures.
20	British Psychological Society	Introduction	It may be useful to clarify what is meant by 'use services' here – whether this refers to only social care (local authority), or to other LD / Mental Health / 3rd sector services here.
21	British Psychological Society	Introduction	The Society believes that it would be vital to include emotional distress as it's not just those with a diagnosed Mental illness/Disorder that hurt or injure themselves – again thinking of the attachment-trauma population or adults on the autism spectrum who can be overwhelmed with distress but are not diagnosed with a mentally illness/disorder / mental health problem.
22	British Psychological Society	Introduction	Whilst there is some value in the aim to measure and improve levels of employment in this group, we believe that inclusion of employment as a measure for people with learning disabilities and mental health problems is also potentially adding an additional confounding variable. This client group is underrepresented in all the employment statistics, often working for nominal amount or at worst having to pay to go to work in social enterprise schemes. Therefore this may not be a great measure of change. We think it would be interesting to capture this information, but it might just be measuring prejudice around LD / other difficulties for this client group trying to gain employment etc. It may be more sensitive and meaningful to capture number of contacts with GP or MH services or LD services rather than just focus on employment.
23	College of Mental Health Pharmacy	Question 1	We think the quality standard accurately reflects the key areas for quality improvement.
24	Royal College of Paediatrics and Child Health	Question 1	It is not clear that this is the case. For example, where is the evidence of benefit of the parent training proposed and what are the elements of content that will make a positive difference?
25	Royal College of Psychiatrists	Question 1	Yes
26	British Psychological Society	Question 1	Notably, the key areas of comprehensive assessment, care coordination, medication review, and (interestingly) parent training programmes are present. However, there is a lack of a clear quality standard around implementing the use of psychological interventions. This means that the range of quality standard can be implemented and people with learning disabilities will not necessarily get the psychological interventions outlined in section 1.8 of the NICE guidance on mental health in learning disabilities. Especially as it is known that people across the population can have difficulty accessing psychological interventions, the Society believes that there needs to be a quality standard statement in this area.

ID	Stakeholder	Statement number	Comments[1]
27	Royal College of General Practitioners	Question 1	The quality standard accurately reflects the key areas for quality improvement. However we are lacking a validated tool for GPs and primary care staff to use to screen for mental health issues in people with learning disabilities. It may be worth it to use " Any recent distress or changes in behaviour without an identifiable physical cause. The annual health check should have a period of time without carers present to ask if anyone is hurting them or making them sad to check for abuse".
28	Behavioural & Developmental Psychiatry Clinical Academic Group, South London and Maudsley NHS Foundation Trust	Question 1	Overall it seems that only a small number of studies have met the threshold for review so as a result the psychological interventions recommendations in the guidance seems very limited. Furthermore, the current quality standard document suggests five main quality standards. The psychological interventions have been even further summarised and there is no reference to psychological intervention at all, or indeed any intervention... medical, or psychosocial. The detailed information regarding the mental health needs of individuals with LD are well documented within the draft and have been known for quite some time. However the information has not necessarily been reflected in service provision or reasonable adjustments by mainstream adult mental health services and indeed primary care. There is a lack of specialist adult services for individuals with mental illness who require admission and although the focus within Valuing People regarding adults with LD accessing main stream adult mental health services the demands for adult beds in some areas is so high and the threshold for admission so acute that LD clients can become difficult to place as the knowledge and understanding within adult services can be very mixed. LD service users need appropriate inpatient services with suitable trained staff. Crisis services able to respond to potential crisis and avoid hospital admissions some home treatment adult services will not accept referrals for clients with LD. Leaving little options for servicer users and families from presenting at A&E departments. Low levels of respite services equally result in hospital admissions the only options The provision of adequate physical health care needs to be inclusive for all health providers but in particular within primary care. Some CCG has utilized the inclusion of a CQUIN target to address physical health. For GP's this has de-incentivized their responsibilities for physical health care for this group of service users

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			1. We would also suggest that the overall recommendations highlighted in the main guidance should be in some way reflected in the quality standards and at the very least make reference to individuals with LD and mental health difficulties accessing treatment.
29	College of Mental Health Pharmacy	Question 2	We don't believe that all organisations currently record this type of information. Some will record the number of patients admitted to LD beds but there may be no information formally recorded specific to this group of people on whether they have had any particular health check or if they are prescribed specific types of medication. Any documentation that occurs is likely to be included in pre-existing, non-LD-specific recording systems, and may be difficult to extract for this cohort. Patients with LD may be also be admitted to an acute service and we feel it is unlikely they would be counted/recorded specifically as having a LD while they were admitted to that type of bed. Various different recording and reporting systems will be in place in various settings and it may not be easy to access data, especially as many clinical records systems do not "talk" to one another. Unless coding of the person with LD occurs accurately, no subsequent data will be available. Definitions will need to be clear as will the parameters to be collected. There could be a role for dashboard reporting.
30	Royal College of Paediatrics and Child Health	Question 2	Annual health checks for people with LD are not mandatory, not all GP practices offer them and they only apply to those aged 14years+ Even where such health checks are undertaken, not every area has systems in place to collect data arising from them. In order to implement this guidance, it would be necessary to MANDATE annual health checks for everyone with a LD regardless of their age, including all children and young people. I suspect there are not the resources in most localities to undertake formal and competent mental health assessments on everyone with LD on a regular basis.
31	Royal College of Psychiatrists	Question 2	People with LD in care settings and living with families are more likely to receive annual health checks including a review of mental health problems. Those with a mild learning disability and living independently are less likely to receive these checks until there is a major crisis. There is a growing awareness amongst GPs to provide annual health checks to people with LD, however there are still gaps in this area. At present there are no CCG wide data that is shared with the LD service. This would be easy to do as the data could be provided to the LD Lead commissioner for monitoring and dissemination.
32	British Psychological	Question 2	Data collection would be possible for certain measures (e.g. hospital admissions; health checks); however, other

ID	Stakeholder	Statement number	Comments[1]
	Society		measures (e.g. quality of life; relationship between carer and person cared for) would be very difficult to collect routinely within current structures.
33	Royal College of General Practitioners	Question 2	NHS England is developing a standard template for annual health checks which should be able to collect the information for Statements 1 and 4. Statements 2 and 3 will need input from data collection for community learning disabilities teams and is likely to be paper based.
34	Behavioural & Developmental Psychiatry Clinical Academic Group, South London and Maudsley NHS Foundation Trust	Question 2	Key systems that could be utilized to collect quality data do exist however it requires a co-ordinated approach between NHS England, Commissioners and Service Providers the requests for quality data constantly changes. A clear set of data reporting indicators would help standardize this and ensure what needs to be collected is and can be used to outline the need for additional services and resources. Unclear if parent training sessions being widely monitored or evaluated.
35	Royal College of Paediatrics and Child Health	Question 3	No
36	Royal College of General Practitioners	Question 3	STOMPLD toolkit is an example of healthcare professionals and carers working collaboratively in tackling the appropriate use of psychotropic drugs in patients with learning disabilities. https://www.england.nhs.uk/2016/06/over-medication-pledge/ Whilst GPs rarely initiate these medications, they have a key role to play in reviewing and ensuring our patients with learning disabilities are only taking drugs if they need to, and that their records indicate why they are taking them, so this guidance is welcome.
37	Behavioural & Developmental Psychiatry Clinical Academic Group, South London and Maudsley NHS	Question 3	Our referral form prompts referrer to provide information regarding an annual health check. Access to assessment by MHLD specialist psychiatrist through referral to our team? STOMP guidance re reviewing medication Etc.

ID	Stakeholder	Statement number	Comments[1]
	Foundation Trust		
38	College of Mental Health Pharmacy	Question 4	We think that the statements would generally be deliverable and in fact in many areas would already be happening, even though recording and reporting will be an issue. There are however pockets of poor practice within all settings, and as alluded to above, it is likely that recording will be especially problematical in non-LD settings. We have some doubts that they would be deliverable within primary care because the numbers of people with a LD is much greater there and there are fewer resources per person with LD. The primary care services are provided by many different providers and co-ordinating the collection of data might be more complicated. It is also the case that there is a dearth of relevant specialist staff in all professions available to work effectively with the LD population.
39	Royal College of Paediatrics and Child Health	Question 4	Not at the moment in all localities, where austerity measures are hitting hard. There are insufficient workers to allocate key workers for everyone with LD and possible mental illness.
40	Royal College of Psychiatrists	Question 4	There is an inadequate provision of awareness and training programmes for parents and carers of people with LD. This is more so where carers/families have communication barriers and may need more individualised provision to ensure equality in service delivery for families from diverse cultural backgrounds. It is not unusual for parents of patients with Learning disability and a mental illness, to themselves have a learning disability. Such parents may also benefit from more individualised provision and tailor made training programmes to address the complex needs of the family as a unit. Unlike, adult mental health services, not all patients with LD with a serious mental illness have a keyworker. Patients are more likely to be known to a local Learning disability service as a whole. The current resources and existing workforce for people with LD and mental illness are not adequate to address the above needs.
41	Royal College of General Practitioners	Question 4	Statement 4 in order to achieve a reduction in antipyschotrophic medication it make require a local approach with pharmacy,. CLDT and carers involvement. It requires considerable discussions with care staff and families who may be concerned that adjusting medication will put the placement at risk. There is useful advice in the following guideline http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2758582/ Whilst some GPs may be able to do theses reductions it is likely to need additional resources in order to help with

ID	Stakeholder	Statement number	Comments[1]
			practices that either don't have the time or the expertise to tackle this issue.
42	Behavioural & Developmental Psychiatry Clinical Academic Group, South London and Maudsley NHS Foundation Trust	Question 4	It is difficult to comment specifically about service users with LD receiving antipsychotic medication perhaps only a small percentage of such service users are under the care of specialist LD mental health teams with the remainder under adult mental health and the diagnosis of LD may at times be more of a professional opinion rather a comprehensive assessment completed in early years. Not all services have specialist services with LD experts in mental illness. The provision of a key worker though possible and likely to be offered again does not come with a guarantee that the worker will have LD expert skills within LD and mental health or has received suitable training and education. The provision of adequate physical health care needs to be inclusive for all health providers but in particular within primary care. Some CCG has utilized the inclusion of a CQUIN target to address physical health. For GP's this might de-incentivized their responsibilities for physical health care for this group of service users. • Specialist LD clinicians i.e. doctors nurses and psychologist • Behavioural Support staff to work with clients with complex LD autism and mental health and associated challenging behaviour. • Crisis intervention teams/ home treatment specific or LD • Access to specialist LD mental health services for service users assessed as requiring specialist support • A structured process of education and training within adult mental health regarding LD/mental health needs • Acute LD mental illness pathway • Acute challenging behaviour pathway different from above avoid hospital admission
43	College of Mental Health Pharmacy	Question 5 (Statement 1)	We do not think that the annual health check of mental and physical health check could be called a comprehensive health assessment as physical and mental health assessment doesn't cover all types of issues that could arise. The standard doesn't specifically list the checks to be completed. To be able to be a comprehensive check we think this should be specifically be defined. This would then prevent any variation between services. An example of an area that might not be covered by physical and mental health assessment could be the person's social situation; where they live and how they are cared for i.e. assessing whether their environment contributes to their health, well-being and development in a positive or negative way. Also, the skills of the person doing the assessment need to be

ID	Stakeholder	Statement number	Comments[1]
			defined more clearly. The comments relating to competencies are not specific enough. Where would these definitions be listed? How many of these potentially multi-skilled people exist? Are there enough? Is there a training need here?
44	National Association of Independent Schools and Non-Maintained Special Schools	Question 5 (Statement 1)	Yes, we would welcome the wording 'comprehensive health assessment' as it implies recognition of parity between physical and mental health.
45	Public Health England Learning Disabilities Observatory	Question 5 (Statement 1)	The term Annual Health Check (AHC) is well-established and is meaningful to many people with learning disabilities and their family carers. We do not think it would be helpful to change this to 'comprehensive health assessment'. This could cause confusion and these are more complicated words to use.
46	Public Health England	Question 5 (Statement 1)	Annual Health Checks could be referred to as comprehensive health assessment but this would imply a more in depth review that needs to consider specific groups within the learning disability sub set.
47	Royal College of Paediatrics and Child Health	Question 5 (Statement 1)	The annual health check can only be called a comprehensive health assessment if it actually is comprehensive.
48	British Psychological Society	Question 5 (Statement 1)	The Society is unsure whether there was a structure currently in place to support appropriately assessing mental health problems within existing annual health checks. Therefore, 'comprehensive annual health assessment' seemed a better descriptor and indicates that this is a step on from existing annual health checks. Note: We felt that just measuring whether people with LD are offered an 'annual health check' (or 'comprehensive annual health assessment') is no guarantee of quality, which it is reported can be highly variable, with some being highly valuable and others not. GPs may need access to refresher training in communication skills and working with adult with LD to ensure annual health checks are sufficiently comprehensive, especially if required to ensure appropriate assessment of mental health needs also. People with learning disabilities may be supported by family members at these assessments, however sometimes the family member supporting an appointment is unable to provide the support one would

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			hope for the assessment. The development of liaison nurse or a dedicated specialist GP in each practice might be a solution, but would of course require additional resources.
49	Royal College of General Practitioners	Question 5 (Statement 1)	We can also call this annual health check a comprehensive health assessment, provided it is carried out competent and experienced individuals who take 1 hour to complete the health assessment and health action plan.
50	Behavioural & Developmental Psychiatry Clinical Academic Group, South London and Maudsley NHS Foundation Trust	Question 5 (Statement 1)	The provision of an annual health check could be called a comprehensive health assessment. The question would be who would co-ordinate this especially if the service user was not open at that time to any specific service other than their GP. Who would complete this and how could this be managed could GP's be given additional training and support around assessment of Mental Illness within LD. Would referrals be sent to adult mental health how would this be managed in terms of additional resources. Where would the outcome of the assessment sit and would it be shared and identified actions delegated out to other services.
51	College of Mental Health Pharmacy	Question 6 (Statement 3)	Various terms such as care co-ordinator or named nurse would be used.
52	National Association of Independent Schools and Non-Maintained Special Schools	Question 6 (Statement 3)	In education, the term 'keyworker' is widely recognised. We would prefer it to 'caseworker' or something with a narrow, health-related meaning.
53	Royal College of Paediatrics and Child Health	Question 6 (Statement 3)	It matters less what the person is called, rather more that there is person-centred care coordination across agencies.
54	British Psychological Society	Question 6 (Statement 3)	The Society believes that the term should be 'care coordinator' to fit in with existing service delivery and avoid duplication/replication of roles/duties, and confusion regarding terminology. 'Keyworker' often refers to a member of staff in a supported tenancy / residential placement. 'Care (or case) Manager' more often refers to a worker within the local authority who may coordinate the (social care) care package. Additionally, the current wording suggests that all people with a diagnosis of a 'serious mental illness' should

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			continue to have a 'keyworker' (or 'care coordinator'). Some people with learning disabilities have such a diagnosis but it has been well managed for a number of years and there have been no concerns about relapse for some time. Providing a keyworker for this group purely because of an historical diagnosis will take resources away from those with more current need. The Society believes that this should be reworded so that it is clear that only people with current or recent need associated with their mental illness must have a keyworker (or 'care coordinator' as this is the preferred term).
55	Royal College of General Practitioners	Question 6 (Statement 3)	Either term is appropriate. It should be clear how much time the person with learning disabilities and mental health issues has access to their key worker as some people in the community have very limited access to their key workers and other professionals may make assumptions that they are providing fun time care for the person with a learning disabilities.
56	Behavioural & Developmental Psychiatry Clinical Academic Group, South London and Maudsley NHS Foundation Trust	Question 6 (Statement 3)	Service users with LD and mental illness will require someone to pull together group of different professionals to help support them back to their pathway of recovery. The term care co-ordinator suggests and best fits such a role and is a familiar term within mental health care services. Overall, we questioned if the standard could go further to not only recommend the involvement of a key worker care co-ordinator but also outline their role within an individual's identified 'treatment/care' plan.
57	College of Mental Health Pharmacy	Question 7 (Statement 4)	After 12 weeks most drugs and dosage forms would have reached steady state. After 12 weeks the effects of the medication could be measured and reviewed. Any time beyond 12 weeks, we would consider to be long term use. The exception to this would be long-acting/depot injections of antipsychotics. They have different pharmacokinetics and take different times to reach steady state so a blanket rule for them does not apply however a statement along the lines that their continuation beyond 12 weeks after they have reached steady state needs to be regularly reviewed would suffice we feel. We note the expectation that antipsychotics will be reduced or discontinued if someone is no longer psychotic however we feel there are issues here. The person may not be prescribed antipsychotics for psychosis – for example they may be being used for mood, or for sleep where someone is not a candidate for other treatment modalities. Also, it may be the antipsychotic that is keeping them well. There is no evidence that medications should necessarily be decreased once someone is well, and in fact this could lead to relapse. We strongly concur that long-term antipsychotic use should be closely monitored and regularly reviewed,

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			and should only be continued if the benefits outweigh the risks, plus the lowest effective dose should be being used, however the quality statement goes too far in this respect. We would suggest wording be amended to not indicate an automatic decrease or discontinuation but that regular review take place (with dose decreases/withdrawal of the agent occurring if clinically indicated) and the lowest effective dose be used.
58	Public Health England	Question 7 (Statement 4)	All people with a learning disability on anti psychotic medication should be reviewed not limiting this to long term use as inappropriate prescribing is as much an issue as ongoing use.
59	Royal College of Paediatrics and Child Health	Question 7 (Statement 4)	We would have thought that anyone on psychotropic drugs should have the need for these reviewed at least every 6 months by a competent mental health practitioner.
60	Royal College of General Practitioners	Question 7 (Statement 4)	6 months symptomatic remission would be the timeframe of long-term antipsychotic drugs.
61	Behavioural & Developmental Psychiatry Clinical Academic Group, South London and Maudsley NHS Foundation Trust	Question 7 (Statement 4)	Antipsychotic medication can vary depending on the individual response to such medication and also the reasons behind it use. Short term psychotic reaction, acute psychosis or long term treatment of a severe and enduring mental illness. Long term usage needs/ should come with long term monitoring by mental health or primary care services depending on the state of an individual's mental health. The use of antipsychotic medication to assist in the management of challenging behaviour needs constant monitoring and reviewing and the use of skilled behavioural support staff should be the first line of response for this group. Hospital admission would have little therapeutic benefit for this service user group
62	Greater Manchester West Mental Health NHS foundation Trust	Statement 1	Where would the responsibility lie for ensuring annual health check data is collected and shared, especially where LD & MH services do not share the same clinical records.
63	Challenging Behaviour Foundation	Statement 1	Pg. 15 states "If they want, the person may take a family member or carer with them". Some people with learning disabilities lack the capacity to decide whether or not to take a family member with them. It would be helpful to reflect this in the quality standard. Family carers have a wealth of information and knowledge about a person's health and medical history. The quality standard should encourage the inclusion of family carers in annual health

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			checks where an individual lacks the capacity to decide who to take.
64	Challenging Behaviour Foundation	Statement 1	It would be helpful to specify at what age annual health checks should start. There is a common presumption that they only apply to adults
65	College of Mental Health Pharmacy	Statement 1	As much as this is a very laudable aim the annual healthcheck may not be a suitable method. The role of the General Practitioner in the health check focusses largely on physical healthcare. That is what it was largely designed for. Many GPs would feel that they are unlikely to have the skills to assess the mental health of a person with LD (PwLD) The role is often delegated to the practice nurse who again may feel unable to make an assessment of the mental health problems. A second issue is what the general practitioner is to do having reviewed the mental health problems. If they are better there needs to be a discussion about reducing and stopping the medication, If they are still a problem there needs to be a discussion about changing the treatment. Either is likely to need some involvement with secondary care . Currently only 50% of PwLD receive an annual healthcheck from their GP. The annual healthcheck is increasing being seen as an opportunity to review a wide variety of other similarly complex aspects of LD care. The programme to stop the inappropriate use of psychotropic medication is suggesting that the Annual healthcheck is also an opportunity to review in depth the need for the psychotropic medications. Perhaps the statement need to go back a stage and state that every person with LD identified in the annual health check as having a mental health problem or receiving psychotropic drugs should be referred for an annual reassessment of their mental state and the continuing need for the psychotropic drug. People with LD are offered a standardised annual health check to include the 'whole person' i.e. physical and mental health and provides the person/carer with a health action plan and provision of accessible information and health promotion literature as appropriate. Family member/carer should be familiar with the person with LD and be aware of their communication style.

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			Whole person annual health check should detail significant events in life of person e.g. change in accommodation/living arrangements, staff changes, death in family, staff, pet, etc.
66	National Association of Independent Schools and Non-Maintained Special Schools	Statement 1	We support all people with learning disabilities having an annual health check and welcome the inclusion of mental wellbeing as part of this check. We would like to see the standard strengthened through explicit reference to those receiving care away from their home area as we know from our members' experiences that children and young people generally miss out on such checks. For children and young people, the health check could helpfully inform the development and review of the 'health' element of their Education, Health and Care Plan.
67	National Development Team for Inclusion	Statement 1	We prefer Annual Health Check (AHC) as this is the term that has been used now for a number of years and people are familiar with it – including many people with learning disabilities and families. Changing it to 'comprehensive health assessment' may confuse people. There is an issue for people with learning disabilities registered with GPs who are not signed up to the Enhanced Service (ES) and we know that only approx. 50% of people with learning disabilities who are eligible get health checks – but putting AHCs in NICE quality standards will raise the profile and even if GPs are not signed up to the ES – an AHC is a reasonable adjustment they should be putting in place.
68	NHS England	Statement 1	a) We understand that currently the annual health checks are offered as part of enhanced GP services. It is not clear how this could be extended to non-enhanced GP services, and therefore risks excluding a portion of the population with learning disabilities who cannot access enhanced GP services potentially contributing to health inequalities. Currently only 200,000 people with learning disabilities are on GP registers. The annual health checks are offered by some GPs as part of enhanced services GPs. b) Annual health checks are only for people 14 years and older. c) Have resource implications for GPs performing the annual health checks and the local authorities providing case workers have been factored into your deliberations d) This would need careful consideration as GPs might need further training to conduct proportionate mental health assessment as part of an annual health check. Young people with autistic spectrum disorder are hard to assess particularly for non-experts. If not carefully implemented this could lead to inappropriate referrals to children and young people mental health services. e) People with learning disabilities are offered an annual health check that includes a review of mental health problems – We wanted to check whether the idea is that this occurs within primary care, as part of the annual health check process, so that any mental health problems can be identified and referred to secondary mental health

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			care if appropriate. As such, it might be better to word it as People with learning disabilities are offered a GP annual health check that includes a proportionate assessment of mental wellbeing.
69	NHS England	Statement 1	The quality statement 1 measure requires clear guidance or delineation regarding what a 'review of mental health problems' should involve in particular with respect of those working with children and young people and their parents/carers. In the absence of such guidance we have no way of assessing the quality or value of such reviews.
70	NHS England	Statement 1	Can this be phrased as a review and proportionate reassessment of MH problems? (proportionate in the sense that it needn't be a full assessment done every year, but that MH needs will need to be reassessed in some cases)
71	NHS England	Statement 1	Final paragraph on page 16 says the person & their healthcare professional must agree a care plan for managing physical health problems. Can we add to this "and mental health problems".
72	NHS England	Statement 1	A professional with relevant expertise is required for statement 2 and not statement 1. Shouldn't they also be involved in the annual review of MH problems in order to properly identify changes in needs?
73	Public Health England Learning Disabilities Observatory	Statement 1	This states that having had an annual health check there should be an "agreed and shared care plan for managing any physical health problems". There doesn't seem to be anything about an agreed and shared plan for managing any mental health problems identified in the check. If an AHC identifies mental health problems then shouldn't the person be put on the Care Programme Approach (CPA)?
74	Public Health England Learning Disabilities Observatory	Statement 1	This quality standard says it covers the prevention, assessment and management of mental health problems in people with learning disabilities in health, social care, educational, forensic and criminal justice settings. There doesn't seem to be anything in this section about how an AHC can be used to help prevent mental health problems. This might include consideration of wider determinants of mental health problems.
75	Public Health England	Statement 1	Include follow up if the offer is not taken up. Also the check needs to identify minor mental health problems as well as reviewing actual mental health problems. The definition of the annual health check needs to refer to specific checks for conditions associated with particular syndromes. Person accompanying may for many also need to be a learning disability professional
76	Royal College of Paediatrics and Child Health	Statement 1	Is a GP reliably skilled enough to identify mental health problems in a person with learning difficulty (LD)?
77	Royal College of	Statement 1	It says healthcare professionals such as GPs and care workers should offer an annual health check. Surely this should

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	Paediatrics and Child Health		just be GPs doing the health checks rather than care workers doing the health checks as care workers won't have the competences required?
78	Royal College of Psychiatrists	Statement 1	Yes. PWLD and a mental illness would benefit from an annual health review. Physical health disorders can have a bearing on mental health disorders. Also PWLD are less likely to seek help for physical health disorders. As the severity of Learning disability increases, patients are less likely to be able to express their discomfort and may present with challenging behaviours. Hence an annual health review which addresses both physical health disorders and mental health review by an expert in learning disabilities is vital.
79	National Development Team for Inclusion	Statement 1	We are not clear why the agreed and shared care plan for managing any physical health problems does not also include mental health problems. Mental health problems may require a referral on to secondary mental health services (as per statement 2) but surely that would be in the plan in the same way that a referral on to secondary health services would be included? Some of the basic things that can be done to improve mental health are also often missing from plans for people with learning disabilities such as contact with others – fresh air and exercise etc – and need more emphasis.
80	Public Health England Learning Disabilities Observatory	Statement 1	AHCs (as part of the Enhanced Service) are already supposed to include a review of physical and mental health. Data is collected about the numbers of people who have AHCs but data about the content is not collected on a national level. It is down to local monitoring where it happens. It is important to note that only about half of people with learning disabilities who are eligible for an AHC get one. Not all GPs are signed up to this Enhanced Service (about 27% are not signed up). How will it be ensured that people registered with a practice that is not signed up to the scheme are still offered an annual health check that includes a review of mental health problems?
81	Action on Hearing Loss	Statement 2	We welcome the rationale behind the quality statement. When providing care for people with learning disabilities, research shows GPs and other care staff are often unaware of the early signs of hearing loss or misdiagnose hearing loss as behavioural difficulties[43]. People who are deaf with mental health problems may need specialist care that takes account of the unique language and culture of the Deaf community, but this isn't always taken into during mental health and social care assessments. For more information and a full list of references, please see comment 1.
82	Action on Hearing Loss	Statement 2	We welcome the recommendation that the assessment should include "a review of the person's previous history both physical and mental health and personal circumstances". Given the higher prevalence of hearing loss in people with learning disabilities and the barriers to communication they may face in seeking help, health and social

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			professionals involved in mental health assessments should be alert to the symptoms of hearing loss and understand the role of the GP in referring people for a hearing test, as stated in the NICE quality standard for mental wellbeing in care homes[44]. People who are deaf with mental health problems may need specialist services that take account of the unique language and culture of the Deaf community. As stated in comment 1, standard tests and mental health measures may be ineffective for people who are deaf if they are unable to communicate well in English, and they may benefit from specialist mental health services with staff trained to communicate in BSL[45]. People who are deaf with mental health problems may also require specialist service planning tools to make sure they have choice and control over their social care and support.
83	Action on Hearing Loss	Statement 2	This section must make reference to NHS England's Accessible Information Standard. For more information on the Standard, please see comment 5.
84	College of Mental Health Pharmacy	Statement 2	This is linked to the answer above. Is this proposed to be an annual check? If it is then as a part of the GP led annual health check the GP needs to receive an assessment from the professional with expertise. Also there needs to be some clarity about the nature of this assessment and every person with LD identified in the annual health check as having a mental health problem or receiving psychotropic drugs should be referred for an annual reassessment of their mental state and the continuing need for the psychotropic drug. Vital that person doing the assessment works within their area of expertise and has relevant experience in working with people with learning disabilities.
85	Greater Manchester West Mental Health NHS foundation Trust	Statement 2	It is not clear whether the standard is referring to a specialist learning disability practitioner or a specialist dual diagnosis learning disability and mental health practitioner. Is the view that as with other dual diagnosis specialists (substance misuse/ personality disorder practitioners) that CCGS would be investing in such posts?
86	Greater Manchester West Mental Health NHS foundation Trust	Statement 2	Where would the responsibility lie for ensuring the annual health checks are completed (local LD or local MH services)
87	Lancashire Care NHS Foundation Trust	Statement 2	Doesn't/not explicit regarding the development of Mental Health services and the collaborative elements. Require definition of 'relevant expertise' as risk of primary care(GP) and MH professionals opting out
88	National Association	Statement 2	We very much welcome the assertion that an assessment by a trained professional should be provided. We note

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	of Independent Schools and Non-Maintained Special Schools		that it is not the role of Quality standards to address training needs specifically but we would note that lack of training will provide a real barrier to the realisation of this standard. There are particular deficits in those with expertise in CAMHS and learning disabilities.
89	National Development Team for Inclusion	Statement 2	There is nothing about how learning disability and mental health services should work together and pool expertise? At the moment, the learning disability psychiatrist (who does have expertise in mental health) usually does these assessments and people with learning disabilities and mental health problems often end up in learning disability services as a result with no sharing of expertise or attempt to reasonably adjust mental health services for people with learning disabilities. This is a big issue – as many mental health services do not see this as their role. We don't see this statement changing anything.
90	NHS England	Statement 2	a) The recommendation for assessment by a professional with relevant expertise requires clear guidance on the skills required by the professionals in particular those working with children and young people and their parents/carers. Some of these skills include but are not exclusive to the following: · Skill and competency to distinguish core symptoms of learning disability from a mental health disorder o Awareness of which core symptoms/ behaviours can also be indicative of other problems: anxiety, attachment, low mood etc. (i.e. differential diagnosis); o Awareness of how core symptoms vary/look different when in the presence of co-morbidity, including co-morbid learning disability with autism and vice versa +/- sensory impairments (or lack of them); o A recognition that a change in symptoms and behaviours is important and should be explored. b) Timing and triggers for an assessment: if the assessment is only for those "with identified MH needs", how are those needs identified in the first place? Saying it's only for those who already have an identified need could exclude those with only suspected MH needs or milder needs. Would it be worth framing this instead around the timing and triggers for an assessment e.g. if a health/social care professional comes into contact with someone with a LD and there is cause to believe the person has MH needs, and they haven't yet had an assessment, they should be referred for one.
91	NHS England	Statement 2	There appears to be overlap between statements 1 and 2, but quality statement 1 (page 16) refers to a care plan to manage physical health problems, whereas the detail on quality statement 2 refers to a mental health plan. Can we clarify for statements 1 and 2: · Are you envisaging a combined physical/mental health assessment or is the intention to have separate ones?

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			· What type of review/assessment is envisaged? · Who undertakes this review/assessment? · What is coming from this review/assessment – a single health plan including mental health? Two separate plans for physical and for mental health?
92	Public Health England	Statement 2	In liaison with a person who has a baseline measure of 'normal behaviour' for that individual. Early recognition of minor mental health problems may not be a specialist. The GP or nurse may identify this during health check.
93	Royal College of Paediatrics and Child Health	Statement 2	Not all trust do have child psychiatrist with expertise in leaning difficulties- this must be made mandatory
94	British Psychological Society	Statement 2	Training is needed to improve the knowledge and skills of MH teams to work with our client group. Alternatively considerable investment and resourcing is required to develop LD teams to also provide increased, dedicated MH support. We have some good examples of joint working between LD and MH services and think this is the model that best fits rather than working around fixed boxes and criteria. Joint working is more person centred. However, unfortunately it is often the systems in health services that prevent this joined up approach – resource issues leave services needing to keep boundaries between overstretched services. There is very poor support for parents whose children are (appropriately) removed but who then need to access to post adoption support. Their Mental Health or emotional distress is often ridiculed or undermined. Poor joint working with Children's services means that these parents can get into a cycle of pregnancies and adoptions.
95	British Psychological Society	Statement 2	This section states to 'Complete a formal assessment questionnaire as part of the assessment'. However it was not clear whether this is an existing specific questionnaire; if so then can this be referenced. If it is not a specific assessment questionnaire being referred to, perhaps best to say 'formal assessment' so staff are not seeking to find a specific questionnaire that doesn't exist (this may be described more fully in the NICE Guideline once published, and if so could be referenced in the quality standard).
96	National Development Team for Inclusion	Statement 2	Should this say - people with learning disabilities and suspected or identified mental health needs have a mental health assessment? The rationale notes the lack of early recognition of mental health problems and the introduction notes that symptoms are wrongly attributed so it is clear that diagnosis isn't always straightforward.
97	Action on Hearing Loss	Statement 3	This section must make reference to NHS England's Accessible Information Standard. For more information on the Standard, please see comment 5.

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98	College of Mental Health Pharmacy	Statement 3	Agree with the sentiments but wonder about the term key worker. In mental health the term used is care coordinator. However we am not sure why the term serious was included here. We don't want to create a whole new industry around defining whether someone has a serious mental illness or just a mental health problem (not serious?) We agree that all PwLD with complex mental or behavioural problems (particularly if they are receiving psychotropic drugs for them)should have a person designated to ensure that they coordinate all aspects of care and communication, and monitor the implementation of the care plan and its outcomes for people with learning disabilities Key worker should accompany person with LD to all assessments etc. and be familiar with person's communication style and their medical history. Key worker should be recognised as a vital part of the team supporting the person with LD. Key worker should be identified in all relevant documentation and health passports etc.
99	Lancashire Care NHS Foundation Trust	Statement 3	The definition of a 'key worker' need to consistent in the terminology applied with clear rational and defintition to the role being described to prevent confusion. Role definition used to denote unqualified support worker in provider settings, care co-ordinator used within CPA (care programme approach) process, case holder used within professional health teams, caseworker used within professional health teams, named worker used within professional and social care contexts
100	Lancashire Care NHS Foundation Trust	Statement 3	The preventative element context of physical healthcare within Mental Health services is not robust and established, therefore there would need to be more explicit reference to the legal aspects
101	Lancashire Care NHS Foundation Trust	Statement 3	What about consideration of commissioning/decommissioning?
102	Lancashire Care NHS Foundation Trust	Statement 3	? difficult to achieve, given the universal skills in Mental Health related to reasonable adjustments
103	National Association of Independent Schools and Non-Maintained Special Schools	Statement 3	We support people with learning disabilities and serious mental illness having a keyworker. We think the statement could be made stronger by expanding the definitions of serious mental illness section to make it clearer how it may express itself in those with complex learning difficulties.

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104	National Development Team for Inclusion	Statement 3	Should this not be the Care Programme Approach (CPA) co-ordinator? The key worker role described is essentially that of a CPA co-ordinator. We accept that not everyone who should have one does – but the CPA co-ordinator role needs to be referenced within this statement as otherwise it risks causing confusion and possible doubling up of roles in some areas. We think the term key worker should not be used in this context as it is often used in social care provider services to describe unqualified support workers who support people on daily living tasks, thus risks creating confusion. The role described in quality statement 3 requires someone with appropriate skills and seniority to ensure the person gets the care they need.
105	NHS England	Statement 3	a) Would it be worth changing this to 'People with LD and a serious and long term mental illness have a key worker'. b) Are there resource implications here? And could there be battles/confusion as to which organisation supplies the key worker? On p23 the note to commissioners might helpfully include 'with responsibility and resource accounted for by the most appropriate body according to the needs of the individual.'
106	NHS England	Statement 3	Small editing note on specifying outcomes: a) Psychiatric hospital admissions reduced; b) transition between and within services is rated easier/is properly planned for?
107	Public Health England Learning Disabilities Observatory	Statement 3	The term 'key worker role' is not the best to use. This term is used a lot in residential care and will have a different meaning in this setting. The terminology used needs to reflect what the person in the role does. This role needs someone with appropriate skills and seniority to ensure the person gets the care they need. Many 'key workers' in residential care would not be placed to do this. As people with learning disabilities and mental health problems should be offered CPA support (http://www.nhs.uk/conditions/social-care-and-support-guide/pages/care-programme-approach.aspx) then shouldn't they have a co-ordinator through this?
108	Royal College of Psychiatrists	Statement 3	Care coordinator is the term used locally in my setting. This is a community nurse who now works as part of a Health Facilitation Team (of two people) for the service covering a population of 206,000
109	Lancashire Care NHS Foundation Trust	Statement 4	Need to be explicit as to the roles and responsibilities of 'prescribers' against those 'who have a role in monitoring/reporting' of symptoms/side effects which may be attributed to long term use/reduction/withdrawal of any medication.
110	Lancashire Care NHS Foundation Trust	Statement 4	Recognition that for the majority of people with Learning Disability 'relaying' what they are 'experiencing' if often difficult and therefore analysis/decisions are often made on observations by others (carers/family/professional) based upon behavioural presentation.

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111	Lancashire Care NHS Foundation Trust	Statement 4	No reference to STOMPLD (Stop Overmedication of People with Learning Disability) agenda/pledge and roles/responsibilities of carers/prescribers of medication
112	Lancashire Care NHS Foundation Trust	Statement 4	Definition of long term use of Antipsychotic medication would depend on the diagnosis and presentation of the patients symptoms against review of the evidence of effectiveness for the given prescribed treatment
113	National Association of Independent Schools and Non-Maintained Special Schools	Statement 4	We very much welcome this standard. We think it could be made even stronger if it indicated that long-term anti-psychotic medication should not be prescribed to people that have not got an official diagnosis of serious mental illness. We know that people with learning disabilities are at a higher risk of being prescribed anti-psychotic medication without having an official psychiatric diagnosis. This standard could be a good opportunity to address this. We would count 'long-term' as being more than 6 months. We would also welcome the standard being strengthened by a recommendation that people taking medications should regularly be given 'medication holidays' to review their condition,
114	National Development Team for Inclusion	Statement 4	We think this statement should also address inappropriate prescription of anti-depressants as well as anti-psychotics.
115	NHS England	Statement 4	We know anecdotally of excessive use of drugs like risperidone for behaviour control and that the SSRIs have few trials with young people and none with LD that we are aware of however, the phrasing here seems quite prescriptive, and seems a perverse instruction if the lack of symptoms is due to anti-psychotic drugs. Would we want to replace with something like: "People with LD will need to have their medication reviewed on an annual/bi-annual basis to ensure the prescription is appropriate and based on a clear need." The rationale section on p25 talks about concerns about antipsychotics but it's not clear what the evidence is that reducing or discontinuing prescriptions is necessarily the best thing, let alone that this ought to be a blanket direction for anybody with LD.
116	Public Health England Learning Disabilities Observatory	Statement 4	Should this also address inappropriate prescribing of antidepressants? This IHaL report relates to both: http://www.improvinghealthandlives.org.uk/gsf.php5?f=313881
117	Public Health England	Statement 4	Should this be all families with a child with a learning disability as mental health problems will not always be evident in early childhood.
118	Royal College of	Statement 4	Since antipsychotics are used for aggressive outburst behaviour in individuals with autism, learning difficulties and

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	Paediatrics and Child Health		challenging behaviour and are not necessarily psychotic it may be better to say 'should be reviewed and if possible reduced or discontinued' rather than as stated.
119	Royal College of Paediatrics and Child Health	Statement 4	This standard seemed to acknowledge that medications may prevent psychotic symptoms and help maintain qoal. A statement needs to add "unless it is felt the medication is significantly preventing behavioural relapse or reducing medication is likely to significantly increase the risk of psychotic symptoms. This needs to go hand in hand with "patients on these medications need to be monitored both for effectiveness of treatment and potential side effects"
120	Royal College of Psychiatrists	Statement 4	Antipsychotics drugs when used for psychosis (including affective psychosis) longer than 2 years and antipsychotic drugs used for anxiety, aggression and other challenging behaviours longer than 3 months without review should be defined as long-term antipsychotic drug use.
121	Challenging Behaviour Foundation	Statement 4	It is important to include children and young people in the data collection to monitor this quality standard. It would be helpful to be able to identify children in the data set to monitor how effective this quality standard is in reducing the use of antipsychotic medication in children who are not experiencing psychotic symptoms
122	Challenging Behaviour Foundation	Statement 4	It would be helpful to define "long-term" to avoid local variations in the application of this quality standard
123	College of Mental Health Pharmacy	Statement 4	As much as this is welcome the findings from the various studies into the prevalence of prescribing of psychotropic drugs in LD is that the prescribing of other psychotropic drugs such as antidepressants, mood stabilisers, and benzodiazepine anxiolytics often in combination is a cause for the concern. This NICE guidance needs to align itself with the campaign (STOMPLD) from NHS England that focuses on all psychotropic drugs A recommended statement should be People with learning disabilities who are taking psychotropic drugs long-term and are not longer experiencing symptoms of their mental problems should have their prescriptions reduced or discontinued following consultation with a specialist The statement from the STOMPLD campaign is as follows: A person centred/individually patient centric approach is necessary when reducing/withdrawing psychotropic drugs. If prescribed for behaviours that challenge there is the expectation that the drugs will stop unless: • There is evidence that the PwLD has gained significant benefit from the use of the psychotropic drug(s) and recent attempts to withdraw the drug(s) has resulted in a deterioration • The nature of the behaviours experienced prior to prescribing psychotropic drug(s) was so severe that withdrawal

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			is considered clinically inappropriate by the carers and others. If the psychotropic drug is prescribed for a mental illness there is the expectation that the drug treatment will follow the recommendations of the relevant NICE guidance. If the PwLD has been symptom free for some time maintenance may not the best course and may need referral to the specialist PwLD team. Care is required when reducing antipsychotic medications in a person who may have been taking them for 10,20,30 years. It is vital to have full access to case/medical notes. Discontinuation should only be attempted by those with specialist expertise in this area. Information on any previous attempts to discontinue antipsychotic medication should be ascertained.
124	Action on Hearing Loss	Statement 5	We recommend broadening the rationale of this quality statement to include other physical health needs including sensory impairments. People with learning disabilities are more likely to develop hearing loss earlier compared to the general population, but this often goes undiagnosed or misdiagnosed[46]. There is good evidence that hearing aids reduce the risk of mental health problems such as anxiety and depression[47]. Early diagnosis is crucial to make sure people with hearing loss get the most out of their hearing aids[48]. For more information and a full list of references, please see comment 1.
125	College of Mental Health Pharmacy	Statement 5	Agree. Those who will use the service/training programmes should be involved in the design of the programmes? They should be asked what their needs are etc. Programmes should advocate a 'whole person' approach to care and ensure both physical and mental health are included.
126	National Association of Independent Schools and Non-Maintained Special Schools	Statement 5	This is the only standard that has a focus on children and young people. We are not convinced that it provides a strong means of improving services and outcomes for children with SEND and mental health problems. Our experience is that many parents are well aware of developing mental health problems but face huge struggles to access provision. We are concerned that the draft standard at present appears to suggest that mental health problems are in some way linked to the quality of parenting received. There is also a heavy focus on observed behaviour. Whilst this is often an expression of a mental health condition, focus on behaviour can lead to conditions being missed – particularly in young people with more profound and complex needs. We think that there could be value in providing sessions for parents to help them recognise when their child may be developing or expressing an unmet mental health need. We know that parents often feel a particular stigma where their child has a disability

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			and a mental health problem and often find it easier to live with the disability diagnosis. This may lead to needs being unrecognised. Work to destigmatise mental health problems for parents and carers might be of value. If the quality standard is to improve outcomes for children with SEND, we suggest an additional statement is needed along the lines of: 'A professional from CAMHS will attend each annual review for any child or young person with a mental health diagnosis and a learning disability, and input the relevant mental health support through the development and delivery of their Education, Health and Care Plan.'
127	National Development Team for Inclusion	Statement 5	Using the phrase 'parents and carers' is potentially confusing as this may be taken to mean paid staff. The rationale also uses 'parents and carers' but then seems to make clear that this is about parents 'training can help parents'. There is a lack of clarity about what training is being suggested. The rationale says it can help parents manage the child's mental health problems but also talks about management of behaviour – which may have nothing to do with a mental health problem. There are some good evidence based parenting programmes – see: http://www.challengingbehaviour.org.uk/driving-change/early-intervention/early-intervention-project.html but we are not clear whether this is what you mean.
128	National Development Team for Inclusion	Statement 5	It is crucial that training for parents is offered in a sensitive way. Parents have told us that they feel their parenting skills are being criticised when they are offered training. This can be because it is offered through generic children's social workers whose main role is safeguarding.
129	NHS England	Statement 5	The recommendation for parent training programmes requires clear guidance regarding what such a 'training programme' should entail. The quality standard would benefit from including more specific guidance about the skills required by professionals. Linked to parent training, post- diagnostic support for families as mandated by NICE should be recommended. The programmes currently in use will have the following elements in common: · What is LD? Origins and natural history · Nurturing the child's development · Managing behaviour to enhance the child's learning and development. · Environmental changes thought to improve outcomes in the short and long term.
130	NHS England	Statement 5	Parenting training programmes must be evidence based in line with NICE guidelines 'Antisocial behaviour and conduct disorders in children and young people: recognition and management' – CG158
131	NHS England	Statement 5	Could we flip the focus to the parents/carers, so: "parent training is available locally for parents and carers of people

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			with a learning disability"
132	NHS England	Statement 5	a) Under outcomes can we add a wellbeing and resilience measure for both parents and carers and those they care for? There are variety of measures to choose from. Please find below some suggested measures Windle, G., Bennett, K. M. & Noyes, J. (2011) A methodological review of resilience measurement scales. Health and Quality of Life Outcomes 9:8. doi: 10.1186/1477-7525-9-8. b) we would recommend the use of parenting stress index as suggested below: Abidin, R. R. (1997). Parenting Stress Index: A measure of the parent-child system. In C. P. Zalaquett & R. J. Wood (Eds.), Evaluating stress: A book of resources (pp. 277-291). Lanham, MD: Scarecrow Press.
133	NHS England	Statement 5	Why is the age only up to 12? Can we change this to 0-18 inclusive.
134	NHS England	Statement 5	On page 40 the final bullet mentions 'the relevant treatment manual'. What is this?
135	Public Health England Learning Disabilities Observatory	Statement 5	It would be useful to define what you mean by carers. This is usually used to refer to unpaid support.
136	Royal College of Paediatrics and Child Health	Statement 5	We have no particular comments about the wording of the statement at this stage, but to note Contact a Family would be interested in working with NICE/RCPCH and others (as appropriate) in the development, delivery and marketing of such parent training programmes. We already have a number of products that could support this aim. Please contact Gethyn Williams, Director of Development and Engagement at CaF, for more details. Gethyn.williams@cafamily.org.uk
137	Royal College of Paediatrics and Child Health	Statement 5	Parent training programmes. It is not at all clear what these are intended to include. What does 'follow the relevant treatment manual' mean? If these are to be delivered outside working hours in community settings with childcare facilities, where do such facilities exist as I do not know of any. It is completely unrealistic to expect parent carers to commit to 12 x 1.5 hour sessions of training when they have their caring responsibilities as well as their own lives to live. Where is the evidence that such programmes are effective and what elements of content have been shown to make a positive difference? The needs of learning disabled children are very diverse. Is this course expected to cover issues ~autism as well??
138	British Psychological	Statement 5	Measuring "Quality of relationship between carer and person being cared for" is highly relevant; however, this

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	Society		would need more detail to assess (and may not be possible to do through local data collection) and may not always be related to mental health problems.
139	British Psychological Society	Statement 5	Overall, the inclusion of a quality statement around parenting training seems positive. However, parenting training programmes are often felt to be "one size fits all" and it may be helpful to consider specialised work that may be needed e.g. parenting programme for children with spectrum conditions or attachment difficulties, programmes that can help address and teach skills around challenging behaviour (e.g. Stepping Stones – excellent but not always used). Specific quality standards around parenting programmes will help. We also need programmes for parents with a learning disability who are raising children (who may also have learning disabilities / difficulties / mental health difficulties / challenging behaviour etc.) to ensure there is equity in support and access.
140	British Psychological Society	Statements 1-4	Statement 1 – 4 are similar to existing practice so increased resources are unlikely to be required. Statement 5 may require additional resources but would have a longer term saving if demonstrated to be effective in reducing long-term/adult mental health prevalence (we were however unsure whether sure the evidence is there yet for this). The most significant resource requirements would be for data collection beyond existing metrics (e.g. introducing routinely collected quality of life measures).
141	NHS England	Additional area	People with learning disabilities and mental health problems are offered a Care and Treatment Review if there is a likelihood of being admitted to a specialist learning disability or mental health inpatient setting. If a Care and Treatment Review is not possible, a 'Blue Light' meeting should take place prior to any potential admission (see policy - https://www.england.nhs.uk/wp-content/uploads/2015/10/ctr-policy-guid.pdf)
142	Action on Hearing Loss	Additional area	We welcome the rationale behind this quality statement. Given the relationship between hearing loss and mental health problems and the high prevalence of hearing loss in people with learning disabilities, more needs to be encourage people check their hearing and seek help. People with learning disabilities may find it difficult to explain their hearing problems to their GP or other care staff due to communication difficulties, which may be exacerbated by mental health problems[37]. Hearing aids are most effective when fitted early[38], so a high level of awareness and regular hearing checks are crucial to make sure people with hearing loss get prompt access to treatment. There is good evidence that hearing aids help people stay socially active and reduce the risk of loneliness and depression[39]. People with hearing loss and people who are deaf may be at risk of worse care and poor health due

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			to poor deaf awareness or the lack of communication support, such as a qualified BSL interpreter. For more information and a full list of references, please see comment 1.
143	Action on Hearing Loss	Additional area	We welcome the recommendations in this paragraph to review physical and mental health, including the effectiveness of existing treatments. People with learning disabilities may find it difficult to seek help for their hearing loss (see comment 2) and may require specialist support. Research shows that 70% of people with learning disabilities have been seen by an audiologist at some point in their lifetime but only 24% receive on-going hearing aid support[40]. As part of the annual health check, Health professionals should carry out hearing checks to identify people who may benefit from a hearing test. Health professionals should also consider whether people already diagnosed with hearing loss need any additional support to get the most out of their hearing aids.
144	Action on Hearing Loss	Additional area	We welcome the recommendation for the annual health check to include a "review of any known or suspected mental health problems and how they may be linked to physical health problems" and an "assessment for conditions and impairment that are common in people with learning disabilities". Hearing loss is a very common condition affecting 40% of people with learning disabilities[41] compared with one in six of the general population[42]. People with hearing loss are at greater risk of mental health problems such as anxiety and depression, but hearing loss often goes undiagnosed or misdiagnosed in people with learning disabilities. People who are deaf or have hearing loss may be at risk of worse care and poor health due to communication difficulties, which may be exacerbated by mental health problems. For more information and a full list of references, please see comment 1. Given the high prevalence of hearing loss in people with learning disabilities and difficulties they may face in seeking help, we recommend rewording the second bullet point to include "sensory impairments". For example, "including the conditions, physical disabilities and sensory impairments that are common in people with learning disabilities"
145	Action on Hearing Loss	Additional area	This section must make reference to NHS England's Accessible Information Standard. The Standard, which is a legal requirement for all NHS and adult social care services as of 1st August 2016, provides clear guidance for providers care on making their services accessible for people with disabilities and sensory loss. The Standard sets out a clear process to make sure people with disabilities and sensory loss can contact services when they need to, communicate well during appointments and understand the information they're given. The Standard also includes the communication and/or information needs of parents, guardians or carers.
146	Action on Hearing	Additional area	Action on Hearing Loss, formerly RNID, is the UK's largest charity working for people with deafness, hearing loss and

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	Loss		tinnitus. 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 their hearing. We help people confronting deafness, tinnitus and hearing loss to live the life they choose, enabling them to take control of their lives and removing the barriers in their way. We give people support and care; develop technology and treatments and campaign for equality. Throughout this response we use the terms 'people with hearing loss' to refer to people with all levels of hearing loss and 'people who are deaf' to refer to people who are profoundly deaf who use British Sign Language (BSL) as their first or preferred language. We are happy for the details of this response to be made public. Action on Hearing Loss supports the broad aims of the quality standard to improve diagnosis and management of mental health problems in people with learning disabilities. Around 40% of people with learning disabilities have hearing loss but this often goes undiagnosed or isn't properly managed[1]. People with hearing loss may find it difficult to communicate with other people and have an increased risk of other mental health problems, for example people with hearing loss have double the risk of developing depression. There is good evidence that hearing aids can improve communication and reduce risk and impact of mental health problems but many people are waiting too to get their hearing tested. People with learning disabilities may find it even more difficult to seek help for their hearing loss due to communication difficulties and may need additional support to use their hearing aids effectively. People who are deaf with mental health problems may need specialist care and support that takes account of the unique language and culture of the Deaf community, but this isn't always taken into account when planning and commissioning mental health and adult social care services for people with other conditions, such as learning disabilities. **Background** There are 11 million people with hearing loss across the UK, about one in six of the population[2]. Hearing loss can be caused by regular and prolonged exposure to loud sounds, ototoxic drugs, genetic predisposition or complications from injuries or other conditions. Age related damage to the cochlear is the single biggest cause of hearing loss. Over 70% of people over 70[3] 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 people with hearing loss. Around 40% of people with learning disabilities have hearing loss and evidence

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			suggests that people with learning disabilities are more likely to develop hearing loss earlier compared to the general population[4]. 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 underestimate. 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[5]. 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[6]. Hearing loss has also been associated with more frequent falls[7], diabetes[8], stroke[9] and sight loss[10]. There is strong evidence of a link between hearing loss and dementia[11]. Evidence suggests that people with learning disabilities are at greater risk of poor health due to their hearing loss[12]. Without a qualified BSL interpreter or other communication support, people who are deaf may be at risk of worse care and poor health. Research by the charity SignHealth[13] shows that over a third (34%) of people who are deaf were unaware they had high or very high blood pressure and more than half (55%) of those who said they had cardiovascular disease were not receiving appropriate treatment. This suggests that people who are deaf may not be getting the care they need due to problems with communication and understanding. Additional research suggests that people who are deaf may be unable to access preventive services and are at greater risk of cardiovascular disease due to the lack of information available in sign language[14]. Hearing loss, deafness and mental health 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[15]. 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[16]. There is evidence of an association between sensory loss

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			and challenging and self-injurious behaviours[17]. People who are born deaf may also be at greater risk of mood, anxiety, personality or developmental disorders[18]. The GP is often the first point of contact for many people who are experiencing mental health problems. Many people who are deaf or have hearing loss struggle to access the GP and other NHS services when they need to due to poor deaf awareness or the lack of communication support. Our Access All Areas[19] 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 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 health professionals 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 are deaf. Research by the Our Health in Your Hands campaign[20] shows more than two thirds (68%) of survey respondents who asked for a sign language interpreter for their GP appointment didn't get one and more than two fifths (41%) felt unclear about their diagnosis because they couldn't understand the sign language interpreter. Standard tests and mental health measures may be ineffective for people who are deaf if they are unable to communicate well in English[21]. Research shows that people who are deaf value specialist mental health services that use medically skilled BSL interpreters[22]. Guidance issued by the Department of Health suggests that more needs to be done to improve the provision of specialist mental health services for people who deaf, as the current level of provision suggests a high level of unmet need[23]. **Diagnosis and treatment of hearing loss** There is good evidence that hearing aids improve quality of life[24], help people communicate, stay socially active and also reduce the risk of loneliness and depression[25]. New evidence suggests they may even reduce the risk of dementia[26]. 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 the average age for referral is in the mid-70s[27]. Delays in treatment mean people with hearing loss are less likely to benefit from hearing aids. Evidence

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			suggests that hearing aids are most effective when fitted early and people with severe hearing loss may find it more difficult to adapt to hearing aids[28]. There are currently no national screening programmes for adults with hearing loss and more could be done to encourage people to seek help and check their hearing. People with learning disabilities may find it even more difficult to report their hearing loss due to communication difficulties, which can lead to misdiagnosis and ineffective treatment[29]. People with learning disabilities may need specialist support to get the most out of their hearing aids. Research shows that 70% of people with learning disabilities have been seen by an audiologist at some point in their lifetime, but only 24% receive on-going support[30]. Research shows that carers for people with learning disabilities are often unaware of the early signs of hearing loss and lack the necessary knowledge and skills to carry out basic hearing aid cleaning and maintenance[31]. Another study[32] reported similar results amongst GPs and other care staff and also found the format of hearing checks carried out in GP surgeries were often inappropriate for people with learning disabilities. The same study found that some GPs were reluctant to refer people with learning disabilities for a hearing test due to misconceptions about the benefits of hearing aids for this group. **<u>The communication and care needs of people who are deaf</u>** People who are deaf who need to access social care for other conditions may need culturally sensitive care and support that takes account of the unique values and culture of the Deaf community. This could include the provision of a qualified BSL interpreter or other qualified communication support, as well as help to attend Deaf clubs or other community groups. Evidence suggests that people who are deaf may be at risk of loneliness and loss of cultural identity if they are unable to communicate in a meaningful way with care staff or other people in care homes. Poor communication or ignorance of Deaf culture could lead to ineffective care and deterioration in health and wellbeing[33]. As a member of Think Local Act Personal Making it Real partnership, we have produced guidance for local authorities on how to deliver personalised care to people with sensory loss, including people who use deaf. For more information please visit http://www.thinklocalactpersonal.org.uk/_library/MakingItReal/MIRSensoryLoss-online-pdf_002.pdf

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			Recommendations In general, the Mental health problems with learning disabilities NICE quality standard must make reference to the following: 1. The relationship between hearing loss and mental health People with hearing loss have increased risk of mental health problems such as anxiety and depression and there is good evidence that hearing aids can reduce these risks. Diagnosing and managing hearing loss and taking hearing loss into account when diagnosing and managing mental health problems are crucial for good communication and care. Hearing loss should be referenced throughout this quality standard as an important consideration for health and social professionals when carrying out annual health checks, mental health assessments and in the overall co-ordination of care between services. 2. The need for specialist mental health services for people who are deaf People who are deaf with mental health problems may need specialist care that takes account of the unique values and culture of the Deaf community. Aside from support to communicate well and understand written information when they visit the GP or other NHS services (see recommendation 3), people who are deaf may also benefit from specialist mental health services which have staff trained to communicate in BSL. When planning and arranging social care for people who are deaf with mental health problems, health and social care professionals should take account of an individual's wishes, feelings and beliefs and show due regard to all aspects of an individual's personal circumstances, in line with the Care Act statutory guidance . We recommend the use of specialist service planning tools to make sure people who are deaf have choice and control over how their social care and support is provided . The requirement for professionals working with people who are deaf or have hearing loss to have specialist knowledge and expertise should be referenced throughout this quality standard and it is particularly relevant for quality statement 2: assessment by a professional with relevant expertise. 3. NHS England's Accessible Information Standard

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			People with learning disabilities and sensory loss may need additional support to communicate well when they visit the GP or access other care services. People with learning disabilities may need information in accessible formats such as Easy Read or support from interpreter or advocate during appointments. People with hearing loss may need care staff to follow simple communication tips such speaking clearly and ensuring their lip movements are clearly visible. People who use hearing aids may benefit from a hearing loop system which makes speech clearer by reducing background noise. A qualified communication professional, such as a speech-to-text-reporter or BSL interpreter should be provided to everyone who needs one. NHS England's Accessible Information Standard , which became law on 1st August 2016, provides clear guidance for providers of NHS care and publicly funded adult social care on making their services accessible for people with disabilities and sensory loss. Accessible communication and information is vital to ensure people with disabilities and sensory loss can participate fully in discussions about their care. We recommend referencing the Standard a key source of guidance in the "Equality and diversity considerations" sections throughout this quality standard. Questions 1. Does this draft quality standard accurately reflect the key areas for quality improvement? We welcome the inclusion of annual health checks and assessment by a professional with relevant expertise as key areas for quality improvement. People with hearing loss may find it difficult to communicate with other people and have an increased risk of mental health problems such as anxiety and depression. Despite good evidence that hearing aids improve quality of life and reduce health risks, many people are waiting too long to get their hearing tested. People with learning disabilities have a higher risk of hearing loss than the general population, yet they may find it even more difficult to get the support they need due to communication difficulties, which may be exacerbated by mental health problems. Annual health checks have an important role to play in ensuring people with hearing loss get prompt access to treatment and on-going support to get the most out of their hearing aids. People who are deaf with mental health problems may need specialist care and support that takes account of the unique language and culture of the Deaf community, but this isn't always taken into account during mental health and social care assessments.

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			2. If the systems and structures were available, do you think it would be possible to collect the data for the proposed quality measures? 3. Do you have an example from practice of implementing the NICE guideline(s) that underpins this quality standard? If so, please submit your example to the NICE local practice collection on the NICE website. Examples of using NICE quality standards can also be submitted. 4. Do you think each of the statements in this draft quality standard would be achievable by local services given the net resources needs to deliver them? Please describe any resources that you think would be necessary for any statement. Please describe any potential cost savings or opportunities for disinvestment. Health and social care professionals may require deaf awareness training to make sure they can communicate well with people who are deaf or have hearing loss and properly implement the requirements of this quality standard. 5. For draft quality statement 1: In line with quality statement 1of Learning disabilities: challenging behaviour Quality Standard (QS101) - could we also call this annual health check a comprehensive health assessment? Please detail your answer. 6. For draft quality statement 3: What term would you use in your setting to describe this role? Key worker? Care or case coordinator? Please detail your answer. For draft quality statement 4: Can you please define the timeframe of long-term antipsychotic drugs?

Registered stakeholders who submitted comments at consultation

- Action on Hearing Loss
- Behavioural and Developmental Psychiatry Clinical Academic Group, South London and Maudsley NHS Foundation Trust
- British Psychological Society
- Challenging Behaviour Foundation
- College of Mental Health Pharmacy
- Department of Health
- Greater Manchester West Mental Health NHS Foundation Trust
- Lancashire Care NHS Foundation Trust
- National Association of Independent Schools (NASS)
- National Development Team for Inclusion
- NHS England
- Public Health England
- Public Health England Learning Disabilities Observatory
- Real life Options
- Royal College of General Practitioners
- Royal College of Paediatrics and Child Health
- Royal College of Psychiatrists