Mental health problems in people with learning disabilities

Consultation on draft guideline - Stakeholder comments table
7 March 2016 – 20 April 2016

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ID	Type	Stakeholder	Document	Page No	Line No	Comments	**Developer's response** Please respond to each comment
1	SH	HQT Diagnostics	Full	General	General	Many mental problems have an underlying physical cause. Before talking therapies and pharmaceutical drugs are used, physical tests should be done. These should include tests for Fatty Acids. Major improvements in mental health have been seen within 3 months of modifying levels of Fatty Acids to achieve: • **Omega-3 Index >8%** • **Omega-6/3 Ratio <3:1** Increasing Omega-3 is relatively easy, but REDUCING Omega-6 involves changes in diet and lifestyle Modify diet to include more oily fish and less oils from Sunflower, Corn & Soya beans Suggest referral and review by	Thank you for your comment. We reviewed the evidence for dietary interventions for mental health problems within this population. There was evidence available for few dietary interventions and these studies demonstrated no evidence of benefit. Therefore we will not be making this amendment.

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						Dietitian (www.bda.uk.com) or registered Nutritional Therapist (www.bant.org.uk) **Sources:** http://www.expertomega3.com/omega-3-studies http://www.fatsoflife.com/ www.hqt-diagnostics.com	
2	SH	HQT Diagnostics	Full	General	general	Many mental problems have an underlying physical cause Before talking therapies and pharmaceutical drugs are used, physical tests should be done. These should include tests for Vitamin D Major improvements in mental health have been seen within 3 months of supplementing levels of Vitamin D so that 25(OH)D is between 100-150 nmol/L **Sources:** www.vitamindwiki.com/Depression	Thank you for your comment. We reviewed the evidence for dietary interventions for mental health problems within this population. There was evidence available for few dietary interventions and these studies demonstrated no evidence of benefit. Therefore we will not be making this amendment.

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						http://www.vitamindcouncil.org/health-conditions/	
12	SH	Royal College of Paediatrics and Child Health	Short	General	General	The Autism guideline (128) recommends systematic assessment at diagnosis of co-morbidities including mental health and behaviour problems — this should be referenced especially as currently there is no encouragement for systematic surveillance	Thank you for your comment. We expect that this guideline will be read in conjunction with other relevant guidelines, including the autism guideline. This is stated within recommendation 1.1.1.
13	SH	Royal College of Paediatrics and Child Health	Short	General	General	The overlap of IQ in the 'normal' range but severe adaptive impairment particularly in autism is a problem not acknowledged as such persons fall through nets of care—who should take responsibility? We wonder whether there is a justification for complete separation of services for LD (which should now be termed ID) from all other services which allow some CAMHS to say they lack expertise in ID?	Thank you for your comment. This guideline specifically addresses the needs of people with a learning disability diagnosis and mental health problems. There is an existing guideline for individuals with autism. The issue of which service is most appropriate for a particular individual needs to be addressed by commissioners at a local level when designing care pathways. We have now included a statement within section 2.1.1 of the full guideline that explains that the term learning disabilities is synonymous with the term intellectual disabilities. It reads 'The term learning disabilities is synonymous with the term 'intellectual disabilities', used commonly within the academic literature.'

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14	SH	Royal College of Paediatrics and Child Health	Short	28	General	Is it more logical for severe to be followed by profound.	Thank you for your comment. The glossary was organised alphabetically, which was why severe LD followed profound LD. The glossary terms have now been changed and now consist of 'learning disabilities' with 'milder' and 'more severe' as subheadings.
15	SH	Royal College of Paediatrics and Child Health	Short	1	General	There are tools for children e.g. DBC so research needs to be more directed to implementation and use — papers published recently by my own group regarding autism.	Thank you for your comment. Our comprehensive review identified evidence supporting only 1 tool for use in children (the DBC). On reflection the GC agreed that implementation and use of identification tools was an important area for research and as such added the research recommendation to "*Develop or adapt reliable and valid tools for the case identification of common mental health problems in people with learning disabilities, for routine use in primary care, social care and education settings*."
16	SH	Royal College of Paediatrics and Child Health	Short	23 24	1.9.7	We agree that medication should be very carefully monitored but the rec that everyone on antipsychotics should be taken off them if no psychosis is against the evidence re value in aggressive outburst behaviour.	Thank you for your comment. We did review the evidence for the use of anti-psychotics in aggressive behaviour and found no evidence in support of this. This recommendation relates to the long-term use of anti-psychotics, which the GC agreed should not be encouraged.
17	SH	Royal College of Paediatrics	Short	General	General	We feel that this is a very wordy document, but with overall good aims — not very specific at times	Thank you for your comments. Whilst the evidence for specific conditions was reviewed, this was sufficiently sparse that the GC were indeed limited in

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		and Child Health				e.g. see comment above re systematic assessment in paediatrics of co-morbidities. Much overlaps with other NICE guidance on psychological therapies, pharmacology, running services, involving service users etc. and it may be time for NICE to consider generic advice which is part of all guidelines! And only publish the specifics for particular conditions. In regard to this, there is nothing about individual mental health problems and ID –except research recs. Can we assume that this is due to lack of evidence rather than evidence of absence of effect?	the recommendations that they were able to make. Where there was sufficient evidence within a particular condition (e.g. CBT for depression), this has been stated explicitly.
18	SH	Royal College of Paediatrics and Child Health	Full	78	4.4	Evidence quoted on page 23 (2.2.1) prevalence of learning disabilities is 2.1%; 1.6%: MLD and 0.4% in SLD for children attending state school. The paediatric referral pathway in the UK allows only SLD to be diagnosed by CAMHS Learning	Thank you for your comment. The school census is the source of these figures.

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						disability team. The MLD are not confirmed. If you are recommending that this paragraph only applies to confirmed learning difficulties patients then would miss out on rest of school age population.	
19	SH	Royal College of Paediatrics and Child Health	Full	101 106	4.6	These recommendations can be divided for children and adults, which would be helpful for the users of guideline.	Thank you for your suggestion. The GC agree that the recommendations within section 1.8 apply both to children and adults. Therefore we will not be making this amendment.
20	SH	Royal College of Paediatrics and Child Health	Full	156 157	5.2.7.1	The entire set of recommendations looks as if addressing for adults. Could there be specifically for children and young people with separate subheading.	Thank you for your comment. There was no evidence for any psychological interventions appropriate only in children and young people, aside from parent training. The recommendations do specify the fact that they apply to all (people rather than adults, or children and young people). The GC agreed that it would be unhelpful to indicate, in the absence of evidence, that some interventions are appropriate only for children or adults, as decisions should be made on the basis of developmental level and individual need.
21	SH	Royal College of Paediatrics and Child Health	Short	22	General	Too prescriptive re number of parent training sessions both with regard to the number and time taken- it is variable depending on what programmes are used and	Thank you for your comment. The wording of the recommendation (now recommendation 1.9.9) is based economic evidence from an economic model on parent training considered during guideline development. The number and length of sessions

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						with regard to the evidence base. Not practical or feasible for most trusts to deliver.	recommended reflect cost-effective provision of parent training according to the economic modelling results, hence they were recommended by the GC.
22	SH	Royal College of Paediatrics and Child Health	Short	27 34	General	Most children will not access IQ measurements and will be defined by broader measures of development and education	Thank you for your comment. The GC agree with the point made here, and we have now amended the wording used in the short guideline to 'milder' and 'more severe', with adaptive behaviour clearly included within these definitions.
23	SH	Royal College of Paediatrics and Child Health	Short	30 34	General	Research to include children and adolescents : research and evidence are needed to address any differences and specifics of case identification or diagnostic tools in this age group with learning disabilities	Thank you for your comment. We agree, and have now amended the research recommendation accordingly. The wording now reads 'tools should be adapted or developed for…depression and anxiety in children and young people'.
24	SH	Royal College of Paediatrics and Child Health	Short	19 34	1.7.1	Paediatric health reviews should not exclude a young person from annual GP checks if adapted to their needs, e.g. difficulties waiting or being in a busy waiting area	Thank you for your comment. This distinction has been made in order to clarify where responsibility lies, and to provide for those who are not already under the care of a paediatrician and so receiving this service.
25	SH	Royal College of Paediatrics and Child Health	Short	18	1.6.24	Wouldn't it be useful to incorporate early warning signs of relapse in to the care plan as a way of recognising mental illness early in learning disabled individuals?	Thank you for your comment. The GC agree that it would be helpful to include this information (if known) when reviewing a care plan. The wording has been altered to incorporate this. The 4th bullet point of revised recommendation number 1.8.23 now reads 'early warning signs of relapse or exacerbation of symptoms, if these are known'.
26	SH	Royal	Short	General	General	Wouldn't it be useful to emphasise	Thank you for your comment. We agree that psycho-

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		College of Paediatrics and Child Health				more on Psycho education of family and carers as this could prove beneficial in the acute phase of treatment and also in relapse prevention.	education can be important, and was an issue that was raised by the carer representatives of the GC. This is addressed within recommendations 1.3.5 and 1.4.2. Involvement of family and carers to help with implementation (and relapse prevention) is also mentioned within recommendation 1.9.4.
27	SH	Norfolk and Suffolk NHS Foundation Trust	Short	General	General	DRIVER Green light tool Kit Firstly we appreciate this is a short version but there doesn't seem much flavour in terms of the essence of promoting the Green light tool kit? That is emphasis on people accessing generic services (mental health) as far as possible in the first instance.	Thank you for your comment. We are unable to recommend particular audit tools such as the Green Light toolkit without high-quality evidence for their effectiveness. Recommendation 1.2.2 has been altered to make explicit the duty of services to make reasonable adjustments and audit their services and now reads '….responsive to the needs and abilities of people with learning disabilities and that reasonable adjustments are made if needed'.
28	SH	Norfolk and Suffolk NHS Foundation Trust	Short	6	30	1.2.6 There is mention of service users who may require inpatient service to receive this locally, however lacks emphasis on prevention of admission to inpatient , promotion of early identification and intervention in first instance.	Thank you for your comment. We agree that prevention and identification are crucial. These issues are addressed within recommendations 1.2.9 (relating to staff training and awareness), 1.7.1 and 1.7.3 (relating to facilitating early identification), 1.6.1 (regular assessment, to facilitate early identification and intervention) and 1.5.1 and 1.5.2 (prevention). Additionally, this guideline should be read alongside others, as per recommendation 1.1.2, where these issues are addressed in detail.
29	SH	Norfolk and Suffolk NHS Foundation	Short	8	9	1.2.10 needs to reflect clinical supervision, opposed to word supervision.	Thank you for your comment. The GC agree that information from service users can be a useful aspect of audits. The wording of revised

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		Trust				Also would request service user feedback and outcomes is also considered a relevant form of monitoring competency	recommendation number 1.2.11 has been amended to make this clearer and now reads 'health and social care staff who deliver interventions for people with learning disabilities and mental health problems should consider using routine sessional outcome measures, including service user reported experience measures'.
30	SH	Norfolk and Suffolk NHS Foundation Trust	Short	8	17	1.2.11 Person centred Goal Based Outcomes (Duncan Law) are presently being promoted as acceptable outcome measures for children and young people LD (children and young people and NSFT are currently exploring this as a min standard).	Thank you for your comment. The measures identified as part of the review did not meet predefined criteria for reliability and validity, or were impractical as a result of the time taken for administration. Therefore no reviewed evidence supported the use of a particular outcome measure (including Goal Based Outcomes), therefore we are unable to amend this recommendation as requested.
31	SH	Norfolk and Suffolk NHS Foundation Trust	Short	8	24	1.3.1 Would suggest services need to use the service users preferred method of communication… Also to deliver the services across the range of setting attended by the service user, not necessarily formal clinic based settings.	Thank you for your comment. We agree that the preferred method of communication should be used. This is stated within bullet point 8 of recommendation 1.3.1. The GC agree that services should be flexible to suit service user needs. We have revised recommendation number 1.8.1 in light of this and it now states that assessments should be conducted 'in a place familiar to them if possible'.
32	SH	Norfolk and Suffolk NHS Foundation	Short	9	23	1.3.2 For children and young people it needs to be determined/established who holds	Thank you for your comment. The issue of establishing parental responsibility is a legal requirement and applies both to people with learning

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		Trust				parental responsibility for them in addition to other consent and capacity factors. Would also suggest information be made available in respect of referral for Independent mental capacity advocate if appropriate.	disabilities and those without. As such we did not believe it was necessary to include this here. Additionally independent mental capacity advocates are provided for within the Mental Capacity Act, and therefore we do not agree that it is necessary to specifically mention them here.
33	SH	Norfolk and Suffolk NHS Foundation Trust	Short	9	30	1.3.3 Need to expand person to include parent/carer/representative. And make every effort to ensure the person understands the purpose, plan and content.. opposed to ensure. And would also suggest to offer information in respect of community advocacy services available.	Thank you for your comment. The GC agree that others such as parents and carers may be involved and as such they are included within the final bullet point of this recommendation. The feedback that we received from service users was that they often still feel that people do not speak to them, or involve them, in decisions about them. Often this was interpreted to reflect an assumption that they were not capable of understanding what was happening. We believe that the use of the word 'ensure' indicates that service user involvement is the expected standard, and that a failure to achieve this should be the exception rather than the rule. Advocacy is now included within recommendation 1.3.1 which reads '…assess whether communication aids, an advocate or someone familiar with the person's communication methods are needed'.
34	SH	Norfolk and Suffolk NHS Foundation Trust	Short	11	24	1.5.1 We would also add in loss of interest in activities they usually enjoy. Also to note, behaviour changes are not always evident	Thank you for your comment. The wording of this recommendation (revised recommendation number 1.7.1) has been altered to specifically mention 'loss of interest in activities they enjoy'. We agree that

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						immediately following loss, bereavement, changes, so the referral/assessment needs to consider timeline/chronology spanning beyond previous few months.	changes in behaviour are not always seen immediately, and this is why a timescale is not specified here. We would expect that this would be done as part of a full assessment (see recommendation 1.8.6).
35	SH	Norfolk and Suffolk NHS Foundation Trust	Short	12	6	1.5.4 Need to factor in level of risk	Thank you for your comment. We agree that risk is an important component within this and that it is covered by the word 'severity'.
36	SH	Norfolk and Suffolk NHS Foundation Trust	Short	12	13	1.5.5 ? Consider how we facilitate access to early intervention in psychosis and related specialist services in accordance with the guideline/standard.	Thank you for your comment. Local service configurations and access points are beyond the remit of this guideline.
37	SH	Norfolk and Suffolk NHS Foundation Trust	Short	13	7	1.6.3 Need to agree a clear objective? Would suggest person centred goal/goal based outcomes with service user is appropriate.	Thank you for your comment. As this relates to the assessment the GC agreed that the current wording is appropriate. Goal based outcome measures are covered within 1.8.23.
38	SH	Norfolk and Suffolk NHS Foundation Trust	Short	14	1	1.6.6 Add in development history, specifically for children and young people as part of the initial assessment, in addition to genogram. Would also recommend to establish previous and present least restrictive/intrusive care/treatment/interventions and	Thank you for your comment. The wording of the recommendation has been altered to mention developmental history specifically (7th bullet point of revised recommendation number 1.8.6 now reads 'review the nature and degree of the learning disabilities, and if relevant the person's developmental history'). Interventions and their success are also covered within bullet point 5. We agree that challenging behaviour and mental health

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						degree of success, in addition to current additional investigations. We would encourage determining that the service user has accessed full range of least restrictive and intrusive interventions/forms of support at this juncture. I.e. SALT (communication strategy), OT (sensory), behaviour support. Although Nice guideline of LD. and challenging behaviour are referred to there doesn't appear to be any cross over with regards to behaviour and mental health. We do require behaviour (functional) assessment for mental health and mental health for behaviour, neither without the other. In addition confirm which appropriate multiagency frameworks that are in place.	are blurred concepts, and the two guidelines should be read in conjunction. Reference is made to diagnostic overshadowing within recommendation 1.8.4. We feel that multiagency frameworks are a consideration at the point of local implementation.
39	SH	Norfolk and Suffolk NHS Foundation Trust	Short	15	1	1.6.8 need to understand the complexity of the situation using complex global formulation(with wider MDT) Would point out at initial assessment advice/signposting and	Thank you for your comment. The GC expect clinicians to use their judgement over the type of formulation produced, and do not agree that it would be appropriate to specify a single form here. Signposting should be documented as per revised recommendation number 1.8.9. Crisis plans are

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						other referrals may be suggested where appropriate, and that these need documenting. Also need to stipulate current arrangement for crisis/contingency in place/available if required.	covered within recommendation 1.8.21.
40	SH	Norfolk and Suffolk NHS Foundation Trust	Short	16	16	1.6.15 We use Cha-PAS (Children and Adolescent Psychiatric Assessments Scale) for children and young people LD, (same as Mini- Passad but for children/young people. This is an assessment tool and one part of our global assessment. We can use behaviour screens to assist with determining mental health/behaviour. We can use the Adolescent wellbeing scale (for depression). We do use adapted tools to gain service users views (adapted) We don't use SDQ for sever/mod LD, its not relevant, reliable or helpful.	Thank you for your comment. The recommendations made were predominantly on the basis of the reviewed evidence. No high quality evidence for the use of the Cha-PAS or the adolescent wellbeing scale was found.
41	SH	Norfolk and Suffolk NHS Foundation Trust	Short	22	24	1.9.3 Suggest access to appropriate community based services such community children's nursing team in first instance that	Thank you for your comment. This is covered within recommendation 1.10.4. We have now altered the wording to make it unambiguous. It now reads 'assess whether support from community and

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						can help with obtaining bloods and based line reference ranges required.	learning disabilities nurses is needed for physical investigations (such as blood tests)'.
42	SH	Norfolk and Suffolk NHS Foundation Trust	Short	23	29	1.9.7 The service user should be recovering monitoring of medication in accordance with guideline? Medication should not be offered in isolation to functional assessment NICE Challenging behaviour and LD page 13 of 57.	Thank you for your comment. Whilst some pharmacological treatments have set monitoring schedules (for example Lithium), the GC and service user focus group agreed that this recommendation was important to improve practice, as many people report that there is no plan for review in place for their pharmacological treatment. The GC chose to make different recommendations for this population of service users in section 1.9 to those set out in the Challenging Behaviour in Learning Disabilities guideline as the recommendations contained within CBLD relate to a specific set of circumstances (challenging behaviour) which are different to the ones that the GC agreed they needed to remedy with these recommendations. Clinicians are expected to choose the most appropriate guideline for the service users they are working with.
43	SH	Norfolk and Suffolk NHS Foundation Trust	Short	General	General	**Other INTERVENTIONS** Sensory profiles are useful to help the service user develop alternative ways of coping and maybe useful to add in.	Thank you for your comment. No evidence was found that would allow the GC to recommend sensory profiles specifically. Therefore we are unable to make this amendment.
44	SH	Shared Lives	Short	10	17	Question 2: It may be challenging	Thank you for your comment. The GC agree that this

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		Plus				to involve all parties. Good that the guidelines include family members and carers. It will be important to communicate the rights of all concerned in deciding who is included in any discussions, and that this is communicated well to everyone	can be challenging in practice, however the GC agreed it was crucial that the expectation would be that services would try and achieve this. The input we received from both carers and service users indicated that they felt that this was very important. We agree that good communication is crucial.
45	SH	Shared Lives Plus	Short	11	3	Question 3: Respite and short break options are very important and a good range of these should be on offer, including for example lesser known options such as Shared Lives short breaks.	Thank you for your comment. The choice of provider for short breaks and respite care is a local implementation issue. Therefore it would not be appropriate to name a specific provider
46	SH	Shared Lives Plus	Short	18	9	Question 2: Integration of care plans can be challenging especially when working across specialities. Therefore good partnership working and adequately supporting and resourcing the key worker role will be essential to ensure this happens.	Thank you for your comment, the GC agree that good partnership working is essential. Revised recommendation number 1.2.3 in particular is designed to encourage partnership working.
47	SH	Shared Lives Plus	Short	General	General	Question 1: Developing professionals with expertise in learning disabilities and mental ill health may have resource implications, but as described in the guidance be a useful role to	Thank you for your comment, the Guideline Committee hope it will help to improve the coordination of care.

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						coordinate care.	
48	SH	Shared Lives Plus	Short	General	General	Question 3: Where appropriate, developing ways of working creatively with little known or underused services provided in the home or community, which the person with learning disabilities and mental ill health is familiar with, such as when living in a Shared Lives arrangement, may overcome communication challenges, be inclusive and optimise the delivery of care.	Thank you for your comment. We are unable to recommend specific service providers without high-quality evidence to support such a recommendation.
49	SH	Humber NHS Foundation Trust	Short	General	General	I have based my comments on the NICE Guideline Short version draft (March 2016).	Thank you for your comments.
50	SH	Humber NHS Foundation Trust	Short	12	1.5.5	The draft guideline states that people with Learning Disabilities who have suspected psychosis or suspected dementia to be referred to Psychiatrists. However, the term 'psychosis' encompasses a wider group of conditions such as bi-polar disorder, severe depression with or without psychotic symptoms, etc. Individuals may also present with psychotic symptoms such as auditory hallucinations which would	Thank you for your comment. The wording of this recommendation (revised number 1.7.5) has been amended to refer to 'serious mental illness' to encompass the wider group of conditions to which you refer.

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						need the expertise of a Psychiatrist to assess, diagnose and treat.	
51	SH	Humber NHS Foundation Trust	Short	12	1.6.1	"A professional with expertise in Mental Health Problems" is mentioned however it is important to define who this professional is and from what professional background they come. Psychiatrists in Intellectual Disability develop the skills and expertise as part of their training and conduct assessments in this regard. Therefore a clarity on this point would be helpful.	Thank you for your comment. The GC decided that as this professional may come from one of several different professional backgrounds and this will differ between different services, that it would not be helpful to specify one particular group in this instance.
52	SH	Humber NHS Foundation Trust	Short	14	1.6.6	DM ID and DC LD are mentioned as the classification systems suggested for use when assessing mental health problems. It should also be borne in mind that ICD and DSM are very much applicable for people with a mild learning disability and have good communication problems. These are the individuals who form a significant number coming to the attention of services for mental health problems.	Thank you for your comment. This recommendation has been amended to include the ICD and DSM-5 and the 11th bullet point of revised recommendation number 1.8.6 now reads 'establish or review a diagnosis using a classification system such as DSM-5 or ICD-10, or those adapted for learning disabilities…'.

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53	SH	Humber NHS Foundation Trust	Short	15	1.6.8	A multi-disciplinary approach to developing a formulation should be adapted.	Thank you for your comment. The GC agree that a multi-disciplinary approach to formulation can be helpful. The need for MDT working is outlined at the start of this section within recommendation 1.8.1.
54	SH	Humber NHS Foundation Trust	Short	16	1.6.14	It is worth noting here that a complete psychiatric assessment should be the basic expectation and norm whilst tools such as the mini PASAD (which was validated using clinical interview as the gold standard) should only be used to support the clinical judgement. It should not be interpreted that mini PASAD therefore is necessary on all occasions where an assessment is undertaken or that it is the instrument of choice.	Thank you for your comment. We have now removed the mini PAS-ADD from this recommendation.
55	SH	Humber NHS Foundation Trust	Short	22	1.9.3	It is essential that medication reconciliation is undertaken prior to prescription and at every review with the prescription issued by the GP.	Thank you for your comment. We refer to the NICE guideline on the safe and effective use of medications 1.10.2 as well as review of medication 1.10.8 within the recommendations.
56	SH	Humber NHS Foundation Trust	Short	23	1.9.7	The initial statement suggests "for people with Learning Disabilities who are taking anti-psychotic drugs and not experiencing psychosis" it must be emphasised that the term 'psychosis' encompasses several	Thank you for your comment. The wording of revised recommendation number 1.10.8 has been altered for clarity and now reads 'for people with learning disabilities who are taking antipsychotic drugs and not experiencing psychotic symptoms'.

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						conditions including schizophrenia, bi-polar affective disorder, depression with psychotic symptoms, schizophreniform illness, etc.	
57	SH	Humber NHS Foundation Trust	Full	176	6.1	In the full guideline in this point there is a mention that anti-psychotics are prescribed in two sets of circumstances either because they have a psychiatric diagnosis or because they have behaviours that challenge. It must be emphasised here that these two groups are not mutually exclusive and that individuals with a significant learning disability with mental health problems may present with challenging behaviours.	Thank you for your comment. We have now amended the wording to make this point clearer and it now reads 'Broadly speaking, people with learning disabilities are prescribed psychotropic drugs including antipsychotics in 3 sets of circumstances: because they have a psychiatric diagnosis, because they have behaviour that challenges or both *(NICE, 2015)'.*
58	SH	Public Health England Learning Disabilities Observatory	Short	General	General	Will there be a link to relevant resources? These should include: Feeling down http://www.learningdisabilities.org.uk/publications/feeling-down-improving-the-mental-health-of-people-with-learning-disabilities-report/ IHaL's reasonable adjustments for	Thank you for your comment, it is not NICE policy to make specific reference to documents or toolkits unless the evidence for these has been reviewed.

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						people with learning disabilities and people with autism who need mental health services and support http://www.improvinghealthandlives.org.uk/mhra/ Green Light toolkit http://www.ndti.org.uk/uploads/files/Green_Light_Toolkit_22_Nov_2013_final.pdf	
59	SH	Public Health England Learning Disabilities Observatory	Short	24 25	General	Sections 1.10 on prevention is remarkably weak and appears tagged on as an apparent afterthought. Given the title of the guidance (Mental health problems in people with learning disabilities: **prevention**, assessment and management), it should precede the section on assessment. To be consistent with a life course perspective, 1.10.2 should precede 1.10.1. Any coherent approach to prevention needs to address: (1) reducing exposure to modifiable established environmental/social determinants of mental health problems among people with learning disabilities; and (2)	Thank you for your comment. We agree that prevention is an important area, and one that should receive prominence. However the wording of this section reflects the available evidence. This section was developed through formal consensus as no good quality evidence was found. We have now re-ordered the recommendations and have moved the section to the beginning of the guideline to emphasise the preventative message.

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						increasing the resilience of people with learning disabilities when exposed to established environmental/social determinants of mental health problems. While evidence specific to people with learning disabilities in this area is sparse, there is no evidence to suggest that children and adults with learning disabilities are immune to the effects of exposure to environmental/social determinants of poor mental health that are well established among the general population (e.g., childhood poverty, violence, discrimination, social exclusion, cf., CMO Report 2103; WHO/Gulbenkian 2014 report on social determinants of mental health). There is, however, moderately strong evidence that children and adults with learning disabilities are *more likely* than their peers to be exposed to such adversities.	
60	SH	Public Health England Learning	Short	5	18	It is essential to be clear that everybody needing mental health services has access to them	Thank you for your comment. Recommendation 1.2.6 explicitly states that services should be available locally.

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		Disabilities Observatory				locally. Historically people with learning disabilities are sometimes not eligible for CAMHs/adult mental health services.	
61	SH	Public Health England Learning Disabilities Observatory	Short	9	29	There is a need for professionals to understand how the MCA and the MHA relate to each other.	Thank you for your comment. We expect that clinicians involved in assessing mental capacity should be aware of the interface between these two important pieces of legislation.
62	SH	Public Health England Learning Disabilities Observatory	Short	13	3	It may be worth highlighting here that LD nurses in particular have a role to play in improving outcomes in people with learning disabilities and mental health problems.	Thank you for your comment. The GC agree that nurses who work with people with learning disabilities have an important role to play in patient care. Local service configurations vary, and therefore we did not believethat it would be appropriate to specify a particular staff group.
63	SH	Public Health England Learning Disabilities Observatory	Short	13	28	Assessment should take into account the person's cultural/ethnic/religious background	Thank you for your comment. Revised recommendation number 1.8.6 has been amended to explicitly include cultural, religious and ethnic background and the fourth bullet now reads 'take into account the person's cultural, ethnic and religious background'.
64	SH	Public Health England Learning Disabilities Observatory	Short	17	14	Risk taking needs to be balanced with other aspects of a person's life. Trying to eliminate all risk from a person's life can have a serious impact on their quality of life.	Thank you for your comment. The GC agree that eliminating all risk will have a negative impact on quality of life. We would expect clinicians to understand this, and are confident that the wording of the recommendations within this section do encourage clinicians to exercise good judgement

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							over whether actions need to be taken to mitigate identified risks (see recommendation 1.8.19).
65	SH	Public Health England Learning Disabilities Observatory	Short	18	15	There is a recommendation about setting agreed outcome measures that are realistic and meaningful to the person to monitor progress. Should there be a point about finding accessible ways to get feedback from people with learning disabilities?	Thank you for your comment. The GC agree that this is crucial, and have now added to revised recommendation 1.2.11 *which now reads* 'health and social care staff who deliver interventions for people with learning disabilities and mental health problems should consider using routine sessional outcome measures including service user reported experience measures' to emphasise the need to seek feedback from service users. This issue is also addressed within recommendation 1.3.3.
66	SH	Public Health England Learning Disabilities Observatory	Short	24	17	Physical exercise has been shown to be a factor in good mental health. Could there be a point added into this section about supporting good physical health in terms of diet and activity levels?	Thank you for your comment. Despite extensive review, no evidence was found that allowed the GC to make recommendations about dietary and physical exercise interventions to prevent mental health problems. However, encouraging people to have a healthy lifestyle, and the provision of advice about diet and exercise, is one of the functions of the annual health check (see section 1.6).
67	SH	Public Health England Learning Disabilities Observatory	Short	24	17	This section talks about people choosing who they live with but there should be a more specific point about the need for people with learning disabilities to be supported in terms of developing relationships. Social isolation can be a factor in relation to mental	Thank you for your comment. This issue was discussed at length by the GC and current wording chosen to reflect the fact that some people do not wish for social relationships, and this should not be forced upon them.

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						health problems.	
68	SH	Public Health England Learning Disabilities Observatory	Short	30	20	There is a need for research around patient-reported outcome measures for people with learning disabilities and mental health problems.	Thank you for your comments. The GC agree that this is an important potential area of research, with scales required for both children and adults, and with versions for rating by service users as well as carers. In the context of a dearth of research we have prioritised other areas of research over this one, however we have now added a standard research recommendation for the development of such measures within the full guideline (see section 5.2.8, 'What experience do people with learning disabilities have of services designed to improve their mental health and how does this relate to clinical outcomes?').
69	SH	British Academy of Childhood Disability	Full	General	General	The scope of this guidance is broad; and covers a wide range of conditions, diagnoses, presentations and interventions. The general principles of care are well described and supported by limited available evidence More detailed guidance should be included with respect to the following issues highlighted below.	Thank you for your comments.
70	SH	British Academy of	Full	261	8.2.6.2	Communication support for individuals in consultations: the	Thank you for your comment. The GC agreed that the potential for someone to be supported by an

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		Childhood Disability		103		opportunity for choosing an individual communication partner should be overtly discussed – with implications for both confidentiality and consent to share information; but also with respect to safeguarding and opportunity to report concerns (although there is mention of this on page 103/351 – the two issues are not linked.	individual that they know and who is familiar with their communication style is covered within bullet point 3 of recommendation 1.3.1.
71	SH	British Academy of Childhood Disability	Full	General	General	There is limited information regarding recognition of sleep disorders and management of sleep in individuals; these are a very common presentation and have a significant impact on mental, physical and psychological help for individuals and parents/carers. Sleep is mentioned related to a few specific conditions/ contexts only (pg 28, 88,195,199,273)	Thank you for your comment. Whilst the Guideline Committee agreed that sleep is an important feature of many mental health problems, it was not considered a mental health problem in itself. In the ICD-10 the most common sleep disorders within the learning disabled population are classified as organic conditions. We have however now included sleep in the introduction to assessment.
72	SH	British Academy of Childhood Disability	Full	General	General	There is limited guidance in recommendations for detailed cognitive assessment; there is mention with respect to dementia (pg 107/110 with TSI and pg 92	Thank you for your comment. Whilst the GC agree that any intervention for mental health problems should be informed by an understanding of the person, they disagreed with the view that a detailed cognitive profile was necessary for this purpose.

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						DMR) but identification of detailed cognitive profile; in particular children and young people with developmental disabilities is essential to understanding their needs and potential impact on mental health. In regular clinical practise there is limited access to review of detailed cognitive function by neuropsychologists and this needs to be addressed in guidance to drive future resource allocation.	They also felt strongly that in many cases a detailed assessment of cognitive profile may not be necessary or helpful, and would have a very significant resource impact. Therefore we are unable to make this amendment to the recommendations.
73	SH	Bradford District care NHS Foundation Trust	General	General	General	PSYCHOLOGICAL INTERVENTIONS SECTION: I believe there should be recognition of the knowledge and skill level required to deliver psychological interventions in the way described in the guidelines. It is Clinical Psychologists primarily who are trained to develop idiosyncratic, holistic and multi-modal formulations and intervene in a flexible, adaptive and eclectic manner to meet the needs of this client group. Without such a recognition my experience is that	Thank you for your comment. We have provided some recommendations relating to the staff training and competencies required to provide interventions (1.2.10). The focus in NICE guidelines is on competence when possible rather than specific staff groups.

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						providers choose to employ cheaper alternatives such as single modality therapists to deliver the interventions you describe, but these therapists very often do not have the knowledge and skills required to deliver the interventions in the way you describe.	
74	SH	Tees Esk and Wear Valleys NHS Foundation Trust	Full	General	General	The section on prevalence conflates learning disability and specific learning difficulty when referencing the 2015 category of special educational needs. This can often result in confusion for service users, parents and carers; the wording should clarify rather than further cloud this issue.	Thank you for your comment. We have checked the source document (https://www.gov.uk/government/statistics/special-educational-needs-in-england-january-2015) and we are satisfied that the wording in the guideline is correct.
75	SH	Tees Esk and Wear Valleys NHS Foundation Trust	Full	General	General	The panel view of the Torrioli study on ADHD, while cautiously worded, is still too optimistic. That study only found a statistically significant difference in one measure of adaptive functioning and even that was merely in one subscale of the tool used (the full scale score showed no difference). The panel state that the study shows a slight improvement of ADHD scores on	Thank you for your comment. It is important to note that the Guideline Committee (GC) base their judgements on both statistical and clinical significance as well as the quality of the evidence. Whilst the GC believe that the evidence statement within the body of the report accurately reflects the strength of the evidence, we agree that this is not appropriately captured within the linking evidence to recommendations (LETR) section. We have now amended the description within the LETR section to ensure consistency with the evidence statement

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						the parent rating but the analysis shows that this is not statistically significant, which does not support the panel's statement. While the panel do not make any recommendations with regard to the study, the supportive statements made ('appears to show' etc.) within the body of the report should perhaps be retracted.	above and it now reads 'The GC noted that the evidence on acetyl-L-carnitine for ADHD in children with Fragile X appeared to reduce ADHD symptoms and have an effect on adaptive functioning. However the study was very small with uncertainty around the estimate, therefore the GC did not think it was appropriate to recommend acetyl-L-carnitine'.
76	SH	Tees Esk and Wear Valleys NHS Foundation Trust	Full	General	General	Very limited evidence base to support the guideline	Thank you for your comments. There is a lack of data available in this area, but the Guideline Committee also hope that the research recommendations can help to rectify this.
77	SH	Tees Esk and Wear Valleys NHS Foundation Trust	Full	General	General	There is a lack of qualitative research into the efficacy of psychological interventions with people with LD. As a result the limited evidence base, recommendations in the guideline draw on research evidence for non LD populations with similar diagnoses and adapt interventions to take account of a person's individual needs, particularly with	Thank you for your comments. There is a lack of data available in this area, but the Guideline Committee also hope that the research recommendations can help to rectify this.

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						reference to their cognitive deficits, communication styles and current levels of understanding.	
78	SH	British Institute of Learning Disabilities	Short	7	1	Question 1: the development of locally available services is very much supported. However, there is the potential for an increase in costs. It is important to ensure that mainstream mental health services will become more accessible to people with learning disabilities. However, the argument for local services is not presented strongly enough in the guidelines.	Thank you for your comment. We agree that the local availability of services is important. We believe the need for people to be able to access services irrespective of whether or not they have a learning disability is addressed within recommendation 1.2.5, which calls for access to all NICE-recommended interventions for mental health problems as well as 1.2.6 which specifically mentions the need for services to be locally available where possible.
79	SH	British Institute of Learning Disabilities	Short	18	21 22	Question 1: we have strong support for people being able to easily access all interventions and services in their mental health care plan. However, this will have cost implications and there may be a danger of commissioners or professionals shaping the care plan to what is available as opposed to what is required by a person with learning disabilities.	Thank you for your comment. This is an implementation consideration beyond our scope. This may be addressed by the NHS England Transforming Care agenda.
80	SH	British Institute of Learning	Short	General	General	Question 2: as already stated, the development of local services that are developed to address the	Thank you for your comments.

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		Disabilities				needs and requirements of people with learning disabilities who have mental health problems. The adoption of proactive identification via making mental health an integral part of the annual health check will lead to an increase in numbers. The increasing acceptance that people with learning disabilities can benefit from a wide range of psychological therapies and interventions will lead to therapists and practitioners having to make reasonable adjustments to enable such opportunities. In addition, the emphasis on addressing the needs of people with learning disabilities who have been prescribed antipsychotic drugs despite not experiencing psychosis is to be welcomed. The commitment to staff training and supervision to enable the specific development of skills, knowledge and experience of learning disability by mental health specialists will make an impact if it is given the priority which will be	

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						required	
81	SH	British Institute of Learning Disabilities	Short	General	General	Question 3: it will be important that resources are targeted on the supports that people with learning disabilities will need to be empowered in accessing and using mental health services, including access to advocacy. Addressing communication issues, delivering information in a wide range of formats, addressing language and cultural requirements will require approaches that historically have not been universally available. The commitment to making "reasonable adjustments" is laudable but this requires a much deeper understanding of the specific needs of people with learning disabilities than has been seen in the past. This guideline will have to challenge the longstanding view that mental health professionals do not possess the necessary understanding to address the needs of people with learning disability.	Thank you for your comment. We hope that the requirement for staff to have an appropriate level of understanding and the necessary communication skills to work with people with learning disabilities and mental health problems (see recommendation numbers 1.2.9-1.2.10 and 1.3.1) will lead to an improvement in care.
82	SH	British	Short	General	General	Question 3: access to structured	Thank you for your comment. Commissioning is a

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		Institute of Learning Disabilities				support as outlined would be extremely beneficial and enable the ongoing skill development to be prioritised. We believe that self-advocacy organisations provide real opportunities in this area and want to see commissioners looking to use their funding in this way.	matter for local implementation.
83	SH	British Institute of Learning Disabilities	Short	1	General	Question 4: the first page outlines "who is it for?" However, there is no mention of people with learning disabilities in the criminal justice system on this page or throughout the guideline. This appears to be a major omission.	Thank you for your comment, the mental health needs of people within the criminal justice system will be covered within the 'Mental Health in the Criminal Justice System' NICE guideline which is due to be published in February 2017.
84	SH	British Institute of Learning Disabilities	Short	8	1 4	Question 4: the guideline asserts that people with learning disabilities can develop mental health problems for the same reason as people without learning disabilities and provides the examples of financial worries, bereavement or relationship difficulties. However, there is no appreciation of their additional vulnerability to poverty, homelessness, hate/mate crime, sexual exploitation, drug and alcohol abuse, loneliness.	Thank you for your comment. These issues are covered extensively within the full guideline (see section 2.5.3 within the full guideline). We would expect that issues are ones that would be considered by those working directly with the person (see recommendations 1.8.5 and 1.8.6) and during a risk assessment (recommendations 1.8.18-1.8.20).

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85	SH	British Institute of Learning Disabilities	Short	5	15	Question 5: we wonder whether the team should be working in "partnership" with people with learning disabilities rather than "in collaboration"	Thank you for your comment. The wording of this recommendation has been altered as requested.
86	SH	British Institute of Learning Disabilities	Short	7 8	21 8	Question 5: There is a need to achieve a balance between recognising that people with learning disabilities can experience mental health problems in similar ways to the rest of the population but additionally their symptoms can develop and present differently. At times, the guideline appears to overstress the differences when it is often the communication issues that cause challenges to overcome.	Thank you for your comment. The GC agree that this is a delicate balance, and believe that the recommendations have covered both sides. However the GC were concerned particularly about under-recognition and diagnostic over-shadowing of mental health problems and so have focussed on this.
87	SH	British Institute of Learning Disabilities	Short	8	7 8	Question 5: Having the knowledge about where to refer is good but all too often the waiting time for appointments or the reluctance of mental health professionals to accept referrals can cause frustration and delays.	Thank you for your comment. We agree that waiting times are a concern. Unfortunately the implementation of recommendations is outside of the remit of the guideline. The aim of this guideline is to set standards which should be taken into account by commissioners when planning services.
88	SH	British Institute of Learning Disabilities	Short	9	1 21	Question 5: Communication to be seen as fundamental to providing great support to people with learning disabilities. There needs to	Thank you for your comment. Recommendation 1.2.10 describes a requirement for staff to be competent. We would expect that an ability to communicate clearly, which we agree is fundamental

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						be more emphasis on training mental health professionals specifically on communication issues. All of these points are valid but it would prove difficult to gain the skills and expertise simply from the guideline advice.	to successfully working with people with learning disabilities, would be covered by this. It is not the remit of the guideline to state how skills should be used, or how the guideline should be implemented, but up to commissioning services and service providers.
89	SH	British Institute of Learning Disabilities	Short	9	6	Question 5: "make adjustments to accommodate sensory impairments" it would be helpful to provide some practical examples	Thank you for your comment. People with learning disabilities may have a wide range of sensory impairments, and these may be compounded by other difficulties. Therefore we were concerned that providing specific examples here would be misleading. Within the assessment section (1.8) it is made clear that staff should find out about these difficulties and factor this into the care plan.
90	SH	British Institute of Learning Disabilities	Short	9	4 5	Question 5: Someone familiar could be an advocate	Thank you for your comment, advocates have now been added to this recommendation.
91	SH	British Institute of Learning Disabilities	Short	9	29 29	Question 5 : We would add advocate, self-advocate or friend to the involvement of a family member, carer or care worker	Thank you for your comment. The GC agree that some of these individuals can also be helpful sources of support and information and therefore we have now included other people who the service user would like to be involved to this recommendation. It now reads 'assess the person's capacity to make decisions…Help people make decisions by ensuring that their communication needs are met (see recommendation 1.3.1) and

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							involving a family member, carer, care worker or other individual familiar with the person's communication abilities (as appropriate)'.
92	SH	British Institute of Learning Disabilities	Short	10	16	Question 5: we would include advocate, self-advocate and friend to the involvement section	Thank you for your comment. We agree that these individuals can also be helpful sources of support and information and therefore we have now included other people whom the service user wants to be involved. The GC agreed that advocates and self-advocates have an important role to play, but that this recommendation does not relate to them and therefore we have not included them here.
93	SH	British Institute of Learning Disabilities	Short	12	24 25	Question 5: we would include an advocate, self-advocate or a person chosen by the individual	Thank you for your comment. The GC agree that these individuals can also be helpful sources of support and information for some people and therefore we have now broadened the wording so that bullet point 2 of revised recommendation number 1.8.1 states 'the family members, carers, care workers and others that the person wants involved in their assessment (as appropriate)'.
94	SH	British Institute of Learning Disabilities	Short	14	28 29	Question 5:we would include advocate, self-advocate or friend	Thank you for your comment. The GC agreed that these people can be helpful sources of support and information but in this instance the GC agreed that it would not be appropriate to these individuals.
95	SH	British Institute of Learning Disabilities	Short	17	7 10	Question 5: this section should identify the purpose of the baseline assessment for all adults with Down's Syndrome, namely to assist with any early identification of	Thank you for your comment. Rationale is not typically included within recommendations. This is detailed within the full guideline (see section 4.6), and we would expect that mental health workers would understand the purpose.

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						dementia	
96	SH	British Institute of Learning Disabilities	Short	20 22	General	Question 5: we believe that the importance of the availability and importance of psychological therapies/interventions should be more strongly emphasised. If we accept the importance of psychological therapies in addressing the mental health needs of the whole population, then this should include making the necessary adjustments to ensure their availability and efficacy for people with learning disabilities. The guideline offers a limited range of psychological therapies as examples. However, the recently published report "Psychological therapies and people who have intellectual disabilities"(February 2016) by the Royal College of Psychiatrists and the British Psychological Society outlines a much wider range of therapies that can be adapted and adjusted to enable people with learning disabilities to participate and gain benefits. This includes	Thank you for your comment. The evidence for a range of psychological therapies was reviewed, however there was very little evidence of sufficient quality to allow the GC to make any recommendations for many of the interventions that you have listed. Where sufficient evidence was available this intervention has been listed specifically.

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						psychodynamic psychotherapy; cognitive behavioural therapy; cognitive analytic therapy; mindfulness and acceptance based therapies; dialectical behaviour therapy; solution-focused brief therapy; systemic psychotherapy; group interventions; art, drama and music therapies.	
97	SH	British Institute of Learning Disabilities	Short	20 22	General	Question 5: there is no link drawn between the importance of access to psychological therapies and Positive Behaviour Support	Thank you for your comment. No high quality evidence was found for the use of Positive Behavioural Support that would have allowed the GC to recommend its' use. It is also important to note that Positive Behaviour Support is not an intervention in itself but more of an overarching approach.
98	SH	British Institute of Learning Disabilities	Short	23 24	29 6	Question 5: we support the guideline's clear steps to ensure that individuals are no longer to be prescribed antipsychotic medication when they are not experiencing psychosis	Thank you for your comments.
99	SH	British Institute of Learning Disabilities	Short	25 26	7 29 1	Question 5: There should be a stronger emphasis on the need for "occupational interventions". We think that "active support" should be included and that there need to be clearer links to organisations that	Thank you for your comment. The GC agreed that support to engage in occupational activities is important and that appropriate support is covered within recommendations 1.11.1 and 1.11.3. The GC wanted to stress the importance of access to mainstream activities, which is covered by bullet

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					13	are good at community bridge building and providing practical support for employment or volunteering. Accessing local mainstream activities should be encouraged much more than attendance at day centres.	point 1 in recommendation 1.11.1. Local availability of services and organisations will vary and so we are unable to provide a list here.
100	SH	British Institute of Learning Disabilities	Short	10	23 25	Question 6: The guideline is very clear about the need to work in partnership with carers. However, this needs building into the training, supervising and mentoring of mental health professionals.	Thank you for your comment. The GC agree that this is an important issue and believe that this is covered by recommendations 1.3.4-1.3.5 and recommendation 1.4.2.
101	SH	British Institute of Learning Disabilities	Short	General	General	Question 7: the draft guideline short version is not always accessible for people with learning disabilities and their family members and carers. It reads as if it is targeted towards mental health professionals and at times uses unhelpful jargon (e.g. page 5 line 19 "provide a person-centred integrated programme of care"). In addition, on page 4, lines 5 – 18 simply listing the relevant NICE guidance can be off putting and unhelpful. This would be better as an appendix.	Thank you for your comments. This version of the guideline is written for professionals and we appreciate that as a result there are a number of technical words and phrases. An 'information for the public' version containing the most important parts of the guideline in a more accessible format is currently in development, and will be published alongside the full guideline. An accessible version of this 'information for the public' document is being produced for service users in parallel.
102	SH	British	Short	General	General	Question 8: the guideline primarily	Thank you for your comment. NICE are

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		Institute of Learning Disabilities				identifies mental health professionals working in health and social care settings as the main source of help and support. There is a lack of reference to local mainstream community based organisations that could provide additional support. In particular, there is a lack of recognition of the potential support offered by advocacy and self-advocacy organisations.	commissioned to provide evidence-based guidance to the NHS and social care, and therefore we maintain that it is appropriate that the guideline is directed primarily at these individuals. Mention has been made of advocacy and self-advocacy at points throughout the short guideline (see recommendations 1.2.1, 1.3.1 for explicit reference, 1.8.1 and 1.8.7 for implicit reference).
103	SH	British Institute of Learning Disabilities	Short	25 26	8 29 1 13	Question 8: A greater emphasis on the use of local mainstream and specialist organisations is required in relation to this section on "occupational interventions".	Thank you for your comment. We have now amended revised recommendation number 1.11.1 in line with this. It now reads '…access local community resources, such as libraries, cinemas, café's and leisure centres'.
104	SH	British Institute of Learning Disabilities	Short	4	17 18	Question 9: There is a lack of recognition that people with learning disabilities who challenge may also have mental health needs that need addressing. Although there is a reference to the separate NICE guidelines on challenging behaviour, there is a lack of recognition that the mental health	Thank you for your comment. We have referred to other relevant guidelines, including the challenging behaviour guideline (*NG11: Challenging Behaviour and Learning Disabilities*). There is also explicit reference to this issue within the full guideline (section 2.4).

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						guidelines might equally apply. The definition of Positive Behaviour Support makes clear that a PBS plan may also include "the secondary use of other complementary evidence based approaches to support behaviour change at multiple levels of the system"(Gore et al; International Journal of PBS 2013 page 16)	
105	SH	British Institute of Learning Disabilities	Short	general	general	Question 9: The guidelines do not address the mental health issues relating to offenders with learning disabilities or who are in the criminal justice system	Thank you for your comment, the mental health needs of people within the criminal justice system will be covered within the 'Mental Health in the Criminal Justice System' NICE guideline which is due to be published in February 2017.
106	SH	British Institute of Learning Disabilities	Short	20 22	general	Question 9: there remains the issue of whether people with learning disabilities can benefit from specific psychological interventions.	Thank you for your comment. The GC agree that this is an important question which further research should look to answer. We have made two high-priority research recommendations that we hope will help to answer this question.
107	SH	British Institute of Learning Disabilities	Short	7	1	Question 9; We have concerns that people with learning disabilities who need acute inpatient treatment for a serious mental illness may not be able to be supported by a "locally available service". There have been major concerns expressed about the negative	Thank you for your comment. We agree that this is a serious issue, and is one that the GC were also concerned about. The need for services to be made available locally has been acknowledged by NHS England (https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/213215/final-report.pdf). The aim of this guideline is to set standards which

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						impact on individuals and their families of placements in assessment and treatment units which are distant from home communities.	should be taken into account by commissioners when planning services.
108	SH	British Institute of Learning Disabilities	Short	general	general	Question 11: we believe that the recommendations that will have the greatest impact include: developing a range of localised services; access to a wide range of psychological therapies/interventions that are adapted to meet the needs of people with learning disabilities; staff training and awareness raising about the best ways to communicate and work in partnership with people with learning disabilities; involving individuals, family members and carers in developing person centred approaches; using the annual health checks to identify and mental health issues; active support and opportunities to access mainstream activities and employment/volunteering with the appropriate support.	Thank you for your comments, the Guideline Committee agree that these are important areas and hope significant improvements are made in these areas, as well as the others addressed by the guideline.

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109	SH	British Association of Dramatherapy	Full	General	general	We are concerned that document may imply that Dramatherapy is not, or will not be, offered to people (children, young people or adults) with a learning disability and mental health problems at assessment or treatment stage, or that Dramatherapy is not an appropriate intervention to be offered to people, and this is not the case.	Thank you for your comment. Despite extensively reviewing the evidence for all interventions the evidence found was limited in both volume and quality. As a result the Guideline Committee were able only to make explicit recommendations for CBT, graded exposure and relaxation. No evidence of a sufficient quality was found for dramatherapy and therefore it could not be recommended.
110	SH	British Association of Dramatherapy	Full	28	General	We are concerned that the supporting evidence may not have included a Dramatherapist's opinion when considering the interaction of factors influencing the development of mental health problems in people with learning disabilities	Thank you for your comment, it was not possible for the Guideline Committee to include representation from every discipline but a wide range of multi-disciplinary professionals were included.
111	SH	British Association of Dramatherapy	Full	33	General	Our association members are members of staff with expertise working with people with learning disabilities and mental health problems, and therefore it is important that Dramatherapists are included in the list of professionals	Thank you for your comment. This is not intended to be an exhaustive list.
112	SH	British Association of	Full	37	General	The implications of the research findings of dramatherapy clinical practice have not been considered	Thank you for your comment. A review was conducted of other therapeutic interventions, which would include dramatherapy, however no evidence

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		Dramatherapy				or referred to explicitly	was found for the benefit of dramatherapy in our population.
113	SH	British Association of Dramatherapy	Full	38	General	Has the guideline committee been in contact with the British Association of Dramatherapy? Have the committee considered liaising with a Dramatherapist or representative for all the Arts Therapies.	NICE will have been in touch with BAD, alongside all registered stakeholders, both when the consultation on the scope began and when the consultation on the guideline began. The committee did not otherwise liaise with any individual dramatherapist but a review was conducted of other therapeutic interventions, which would include dramatherapy. No evidence was found for the benefit of dramatherapy in our population.
114	SH	British Association of Dramatherapy	Full	84, 95, 97	General	We are concerned that consideration of Dramatherapy or arts therapies specific assessment tools, as an appropriate structure for assessment, have been omitted in this review	Thank you for your comment. Despite a comprehensive review covering all tools relevant to people with mental health problems and a learning disability, few tools specifically adapted or developed for people with learning disabilities and mental health problems that met our criteria for sensitivity and specificity were found. No specific dramatherapy or arts therapy tools were found.
115	SH	British Association of Dramatherapy	Full	114	General	We are concerned that Dramatherapy or Arts Therapies have not been referred to in this review of psychological interventions. Many of our association members are working in psychological services, or inputting into psychological service teams from established arts	Thank you for your comment. No evidence was found for the benefit of Dramatherapy, and for this reason no recommendations could be made for it. We disagree that all listed interventions require verbal communication (see recommendations 1.9.6-1.9.9). The principles for psychological interventions (see recommendations 1.9.2-1.9.4) also allow for a wide range of strengths and difficulties, and appropriate adaptations to accommodate these.

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						therapies teams. Omitting access to non-verbal therapies in this review implies that people with learning disabilities and mental health problems only access talking therapies which is not a true reflection of the current situation.	
116	SH	British Association of Dramatherapy	Full	General	General	Our association has experience of implementing Dramatherapy in a range of areas relevant to this document and we would be willing to submit our experiences and share our evidence. Please contact seren.grime@wales.nhs.uk or Vicechair@BADth.org.uk	Thank you for your comment. All stakeholders were invited to submit evidence during guideline development. We are no longer in a position to accept submissions of evidence at this late stage of the guideline development period.
117	SH	London Fire & Emergency Planning Authority (LFEPA)	Full	General	General	London Fire Brigade (LFB) welcome the opportunity to comment on the draft guideline '**Mental health problems in people with learning disabilities**' which include adults, children and young people and covers the care provided in various settings. Adults, children and young people with learning disabilities/mental health issues as well as professionals who have direct	Thank you for your comment. We agree that fire risk may be greater in people with learning disabilities and mental health problems than within the general population. Fire risk is covered within recommendation 1.8.18 which refers to both risk to self and risk to others.

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						contact with them, and make decisions concerning their care are of particular interest to LFB. This is due to the increased risk from fire, fire deaths and injuries for people with care and support needs arising from mental health issues which often coexist with physical impairments and social/economic factors. We have worked with several organisations including Skills for Care, the UK Home Care Association, the Care Quality Commission and the Prime Minister's Dementia Challenge Group to raise awareness of these fire risks and the means to reduce them. The work with Skills for Care led to knowing how to identify and reduce risk for people with care and support needs being a requirement of the Care Certificate for care staff. However, our evidence demonstrates that opportunities have been missed by care and support agencies.	

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						We would therefore ask that the guideline includes reference to/requirement for an assessment of fire risk as part of the effective care planning process and contains a prompt to contact the local fire and rescue service for advice on reducing fire risk tailored to the person's needs and circumstances.	
118	SH	London Fire & Emergency Planning Authority (LFEPA)	Full	105 108	General	We are concerned that professionals/ practitioners may not be equipped with the necessary knowledge/tools to assess (fire) risk comprehensively when faced with self-neglect cases. There is evidence to suggest that there is a correlation between people with self-neglect behaviour (in particular hoarding) and an increased risk of a fire starting and spreading. There is need for a better defined (assessment) framework within which professionals/ practitioners can operate when faced with individuals at high (fire) risk. The rationale for including fire safety	Thank you for your comment. This is outside the scope of this guideline.

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						within self-neglect spectrum (in particular hoarding) lies with the significant risk that such behaviour present not only to the individual but also to others. The London Fire Brigade advocates prevention strategies	
119	SH	London Fire & Emergency Planning Authority (LFEPA)	Short	6	5 6	Sharing information is a driver for collaboration; yet, it is often highlighted as a difficult area of practice. Existing data protection legislation is often quoted as a barrier to information sharing and an explicit duty to share risk information and a more comprehensive approach is required not only to increase access to data, develop and maintain cooperation across agencies; but to develop the strategic and coordinated intelligence necessary to tackle concerns around the care, safeguarding and risk management of vulnerable children, young people and	Thank you for your comment. We agree that information sharing is an important area of practice. Information sharing should always be according to Caldicott principles and in accordance with the Data Protection Act. It would not be appropriate for us to comment on existing legislation. The guideline does make a number of recommendations in section 1.3 of the Short guideline about appropriate ways to include family, carers and advocates in the care of people with learning disabilities, as well as other services/staff.

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						adults.	
120	SH	HFT	Short	5	23	Pathways should identify procedure when a person refuses effective care.	Thank you for your comments. The issue of service user choice is addressed within recommendations 1.3.2-1.3.3 on capacity.
121	SH	HFT	Short	7	7	Local MH services reflecting what local health service procedures can deliver – especially in crisis situations.	Thank you for your comment. This recommendation developed, in part, from an awareness of the limited access to information that staff such as crisis workers, may have. This must be balanced with the required level of knowledge to be able to provide effective assessment or care. The GC decided that this recommendation does successfully balance the two.
122	SH	HFT	Short	8	13	Interventions should also be accredited for consistent safe practice. The cost to service providers who train all their staff is substantial. The use of physical interventions rely on service providers standards of good practice and should evidence effective monitoring & review of interventions.	Thank you for your comment. Interventions that are not safe should not be provided. It is the responsibility of service providers to ensure that their staff are appropriately trained to provide safe and effective care. This upfront cost is both necessary and reasonable, and may result in cost savings later on as a result of more efficient and effective care.
123	SH	HFT	Short	10	7	Possible outcome if the person refuses treatment options. The impact on their health and situation	Thank you for your comment. This issue is covered within the section on consent and capacity (1.3.2-1.3.3) as well as associated legislation.

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						(home/lifestyle) & may result in isolation, reduction in paid support.	
124	SH	HFT	Short	13	6	Identify an acceptable way to share concerns with carers (family/paid) other health professional to affect support.	Thank you for your comment. Please see recommendations 1.3.4-1.3.5 which stress the importance of family and carers in developing and implementing support.
125	SH	HFT	Short	13	16	A person may refuse to a health assessment- records, carers, others may be consulted (or not).	Thank you for your comment. Recommendations 1.3.2-1.3.3 discuss the issue of consent and capacity, and should be read in conjunction with relevant legislation. Data collection from records and carers is provided for within recommendation 1.8.6 and 1.8.7.
126	SH	HFT	Short	16	27	Include carers (paid and unpaid) involvement to evidence changes to behaviour early to enable referral from GP. Many people are referred later when behaviour is reaching crisis and then the funding authority may move the person as they need more support & cannot consent .	Thank you for your comment. This section of the guideline addresses assessment tools that may supplement a clinical assessment. However the involvement of other people, including carers, to collect important information about a person is covered within recommendation 1.8.7.
127	SH	HFT	Short	17	13	To add risk of isolation.	Thank you for your comment. The GC agreed that social isolation is covered within revised recommendations 1.8.6 and 1.8.8.
128	SH	HFT	Short	21	10	Funding for everyday life has been reduced or non- existent-key times are seen as the priority by funding authorities.	Thank you for your comment. We are aware that this is an area of concern. Funding is a national policy issue and beyond our remit.

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129	SH	HFT	Short	21	18	Costs for supporting a person to and during appointments may affect a person's weekly paid support hours/family work hours which may be over many months. Flexible funding to enable a person to 'save' hours for appointments from their annual budget may be useful.	Thank you for your comment. We are aware that this is an area of concern. Funding is a national policy issue and beyond our remit.
130	SH	HFT	Short	24	13	Personalised technology to support a person to retain independence and enhance their safety at home should be considered when assessing person's budget. Technology to access medical appointments can be considered when a person is isolated or refusing a formal meeting. The cost can be adjusted to the person's needs-if this is not offered by the provider/local authority then it is generally not looked for by the person themselves or their families..	Thank you for your comment. The issue of personal budgets and their allocation is a local implementation issue and beyond our remit.
131	SH	HFT	Short	24	20	The physical environment should also reflect the needs and safety of the individual and taken into consideration when care	Thank you for your comment. The requirement to take into account the service user's needs and safety is addressed within bullet point 2 of recommendation 1.5.1.

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						placements are considered..	
132	SH	HFT	Short	25	8	Costings are a major factor in accessing and staying included in local activities/resources. Many people on benefits are unable to purchase leisure activities on a regular basis- the cost of the activity plus transport plus possible support, etc. add to the overall cost.	Thank you for your comment. We agree that this is an area of concern. Disability benefits are a National policy issue and beyond the remit of the guideline.
133	SH	Neonatal and Paediatric Pharmacists Group (NPPG)	general	General	General	We welcome the development of this guideline.	Thank you for your comments.
134	SH	Neonatal and Paediatric Pharmacists Group (NPPG)	general	General	General	We agree with the research recommendations.	Thank you for your comments.
135	SH	Southern Health NHS Foundation Trust	General	General	General	Has the latest guidance from the British Psychological Society and the Royal College of Psychiatry on LD and mental health, edited by Nigel Beail been considered? Art Psychotherapist: "I think it underlines the importance and need for a robust and cohesive MDT. I would argue that the more	Thank you for your comment. A number of the authors of the guidance that you mention were involved in the development of the guideline, either as GC members or advisors. We agree that a well-skilled workforce is crucial for the effective delivery of care in any patient group. The competencies identified by the Guideline Committee as being important for all intervention

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						skills and therapy approaches a team has the more responsive and person-centred they are able to be for the LD population which often has complex presentations. The NICE guidance already acknowledges there is little evidence and points out the need for further research. This may always be a problem so we would like to see them focus/pay attention to the skills, competencies and knowledge within an MDT that are strengthened by different professions working together."	staff working with people with learning disabilities can be found within recommendation 1.2.10. Service delivery models will vary locally. This is an implementation issue beyond our remit.
136	SH	Southern Health NHS Foundation Trust	Short	General	General	There is frequent reference to co-ordination of health and social care. Do NICE have a recommendation regarding whether co-location or integration are preferable arrangements to facilitate this?	Thank you for your comment. We did conduct a review of the evidence to ascertain what service models are most effective, however no evidence was found that answered this question. Therefore this i a matter for local implementation.
137	SH	Southern Health NHS Foundation Trust	Short	General	General	This guidance sets out and broad general principles that need to be considered when supporting people with a Learning Disability and Mental Health Needs. More specific detail would be helpful re:	Thank you for your comment. Local service configurations and interface are an implementation issue and beyond the remit of this guideline. Within the boundaries of the guideline remit, however, we have made a recommendation for the employment of key workers to assist people with learning

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						processes for managing and coordinating multi-Professional and Multi-Agency processes to support the mental health needs of people with a learning disability. Links need to be drawn between this guidance and National Frameworks such as CPA, Green Light Toolkit and an emphasis on working with Recovery Models (e.g. WRAP) would be welcome. A greater emphasis on identifying, assessing and Managing Risk including approaches to Positive Risk would also be welcome.	disabilities in accessing the support laid out within their care plans (recommendation 1.2.8). We are unable to recommend particular audit tools such as the Green Light toolkit without having reviewed high-quality evidence for their utility. However recommendation 1.2.2 has been altered to make explicit the duty of services to make reasonable adjustments and audit their services and now reads '…ensure that care is responsive to the needs and abilities of people with learning disabilities and that reasonable adjustments are made if needed, and regularly audited to assess accessibility and acceptability'. We believe that risk assessment is covered adequately within 1.8.18.Similarly we do not recommend named approaches without good evidence, so would not be able to recommend WRAP. We maintain that our risk assessment section is both sufficient and balanced (recommendations 1.8.18-1.8.20).
138	SH	Southern Health NHS Foundation Trust	Short	1	2 4	The title of this Guidance refers to 'prevention, assessment and management'. Prevention is a key factor in supporting people with a learning disability to maintain good mental health. However there is no reference to approaches that	Please see section (1.5) within the short guideline for recommended prevention strategies. We appreciate this comment. However 'problems' is the approved NICE wording and is used consistently across all NICE guidelines. Therefore we are unable to make this amendment.

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						should be considered re: prevention within the guidance. It would be helpful for this to be included in section 1.2 It would be more positive to refer to Mental Health Needs rather than problems.	
139	SH	Southern Health NHS Foundation Trust	Short	4	4 16	It is important that this Guidance links with existing guidance. However existing guidance does not relate specifically to the Learning Disability population and reasonable adjustments are not always in place within Generic Mental Health Services to enable recommendations to be met. Will this be addressed in Future revisions of existing guidance?	Thank you for your comments. We are unable to comment on the scope of guidance NICE are likely to commission in the future, however it is the purpose of this guideline to set out the adjustments that should be made for people with learning disabilities and mental health problems.
140	SH	Southern Health NHS Foundation Trust	Short	5	1	Could this include Diagnostic overshadowing?	Thank you for your comment. The phrase "differences in presentation of mental health problems" here relates to diagnostic overshadowing. The concept is also covered later in the guideline (1.2.9 and 1.8.4).
141	SH	Southern Health NHS Foundation Trust	Short	5	2	Could this be expanded to refer to communication abilities and preferences. This section should also include consideration of Physical Health needs.	Thank you for your comments. Physical health was outside of our scope and remit, and therefore we were unable to make any recommendations in this area.

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142	SH	Southern Health NHS Foundation Trust	Short	5	10	Should this section include reference to the Green Light Toolkit?	Thank you for your comment. We are unable to recommend particular audit tools such as the Green Light toolkit without having reviewed evidence for their utility. Recommendation 1.2.2 has been altered to make explicit the duty of services to make reasonable adjustments and audit their services and now reads 'The designated leadership team should ensure that care is…responsive to the needs and abilities of people with learning disabilities and that reasonable adjustments are made if needed and regularly audited to assess effectiveness, accessibility and acceptability'.
143	SH	Southern Health NHS Foundation Trust	Short	5	11 17	What is NICE'S Position on the use of CPA and how does this link with the Designated Leadership Team? This is a National Framework for coordinating care for people with complex Mental Health Care Needs but is not referred to specifically in NICE Guidance. It would be helpful to include Advocates in the leadership team.	Thank you for your comment. We acknowledge that CPA is used nationally, however it was the view of the GC that as CPA refers solely to secondary mental health services that it would be unhelpful to mention it here. The GC decided that it has variable utility at a local level, and so did not wish to make specific recommendations about the use of CPA.
144	SH	Southern Health NHS Foundation Trust	Short	6	12	Would greater definition of outcomes related to 'harm' be useful?	Thank you for your comment. The definition of harm may vary by service and therefore we do not agree that a definition would be helpful here.
145	SH	Southern Health NHS	Short	6	25	Question 1: This may constitute a significant increase in cost through	Thank you for your comment. We expect that services will provide appropriate training to their staff

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		Foundation Trust				staff training. It would be interesting to establish how many services have a workforce currently trained to offer all interventions recommended by NICE. Are all intervention adaptable for people with a Learning Disability?	in order to provide a good service to patients. Services available will vary at a local level, depending upon what is commissioned. The aim of this recommendation is to make it clear that people with learning disabilities should not be barred from services purely because they have a learning disability. It is expected that clinicians will exercise judgement as to which interventions are appropriate for a given individual.
146	SH	Southern Health NHS Foundation Trust	Short	6	27	Should links be drawn here with the Green Light Toolkit?	Thank you for your comment. We are unable to recommend particular audit tools such as the Green Light toolkit unless we have reviewed the evidence for their utility. Recommendation 1.2.2 has been altered to make explicit the duty of services to make reasonable adjustments and audit their services and now reads 'The designated leadership team should ensure that care is…responsive to the needs and abilities of people with learning disabilities and that reasonable adjustments are made if needed and regularly audited to assess effectiveness, accessibility and acceptability'.
147	SH	Southern Health NHS Foundation Trust	Short	7	1 4	What happens when local services are not available. Is there a responsibility here for Commissioners to be taking this into account?	Thank you for your comment. Availability of services will vary locally. The aim of this guideline is to set standards which should be taken into account by commissioners when planning services.
148	SH	Southern Health NHS	Short	7	6	This is rather limited. Should this include family history, impact of	Thank you for your comment. This recommendation refers to the basic level of knowledge and

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		Foundation Trust			10	significant life events, changes in social networks and living environments, socio-economic factors, areas of risk and potential vulnerability.	understanding of the service user that any staff member coming into contact with them should have. We agree that different staff, with different roles and levels of involvement, are likely to require a more in depth understanding of the person. The GC do not believe that all staff would require the knowledge and understanding that you suggest, and so will not be making this amendment.
149	SH	Southern Health NHS Foundation Trust	Short	7	11 19	Does NICE have any recommendations about the role of multi-agency care co-ordination? In some geographical areas, only health staff are able to co-ordinate CPAs. This does not seem useful, particularly in cases where safeguarding concerns and risk management are paramount. How does the Term Key worker relate to the CPA Care Coordinator?	Thank you for your comment. The GC noted that there is local variation in the way that CPA is implemented and that it is specific to secondary mental health services, therefore they decided that it would not be helpful to reference it. Care coordination is the subject of section 1.2 of the short guideline.
150	SH	Southern Health NHS Foundation Trust	Short	8	1	It would be positive to see recognition of the various factors contributing specifically to the LD population developing mental health problems, as well as universal factors that apply to the general public e.g. lack of social participation, lack of autonomy, limited opportunities for work – is	Thank you for your comment. These factors are described in greater detail within the full guideline with references to the corresponding literature (see section 2.5.3 of the full guideline). We would also expect that issues are ones that would be considered by those working directly with the person (see recommendations 1.8.5 and 1.8.6) and during a risk assessment (recommendations 1.8.18-1.8.20).

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						there evidence about this?	
151	SH	Southern Health NHS Foundation Trust	Short	8	13	Reference to 'relevant manuals' - Would it be better to refer to interventions that are evidence based , Assessment Tools where possible should have been validated for use with people who have a learning disability and staff trained appropriately to use them.	Thank you for your comment. This wording was chosen as the evidence base in this population is limited, and to word this in this way may result in service users being denied interventions. We agree that tools should be validated and staff trained appropriately, and have stated this within recommendations 1.8.12-1.8.13.
152	SH	Southern Health NHS Foundation Trust	Short	8	17 19	Are there any specific outcome measures that NICE would recommend?	Thank you for your comment. The evidence base for assessment tools and outcome measures was reviewed. Few studies meeting our inclusion criteria were identified, and of those tools many had poor reliability and validity within our population, or were not practical in terms of time taken to administer. Therefore, on the basis of the reviewed evidence the GC were unable to recommend any specific tools. Please see section 4.5.2 of the full guideline for details of this review.
153	SH	Southern Health NHS Foundation Trust	Short	8	20 22	Reference to Mental Health Assessment could suggest that there is one assessment. This doesn't reflect the range of areas that need to be considered and the variety of assessment tools that may need to be used. Would it be better to refer to Assessment of Mental Health Needs? Treatment is	Thank you for your comment. The GC were confident that the heading would be clear to clinicians and therefore will not be making this amendment.

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						quite a medical term. Could this refer to Interventions?	
154	SH	Southern Health NHS Foundation Trust	Short	9	1 21	There is a strong reliance here on verbal communication which can present significant challenges for people with a learning disability. Reference should also be made to non verbal factors that could inform the assessment of need e.g. physical appearance, changes in behaviour, cultural factors that may influence how symptoms are described and understood. Could more detail be added re: reasonable adjustments to accommodate sensory impairments e.g. sensory impairments range from physical disability re:sight / hearing impairments to complex conditions ADHD, Autism. Consideration should also be given in this section to working with people who are difficult to engage – what reasonable adjustments are required to support people to attend appointments / meetings?	Thank you for your comment. The feedback received from our service users was that they are often spoken about rather than spoken to, and that they find this understandably distressing. It is for this reason that recommendation 1.3.1 precedes the sections on assessment and intervention. However, non-verbal factors and other sources of information potentially relevant to assessment can be found within section 1.8, and specifically within recommendations 1.8.1, 1.8.4, 1.8.6 and 1.8.7. Reasonable adjustments will vary depending upon the individual and their needs. Therefore the GC agreed that it would not be possible to provide a list of appropriate adjustments. Clinicians are expected to have the skills to make this judgement, as set out in 1.8.1 (assessment) and 1.9.2 (psychological interventions). Issues around engagement are dealt with in section 1.3 (see recommendations 1.3.1-1.3.5).
155	SH	Southern Health NHS	Short	8	1	It would be positive to see recognition of the various factors	Thank you for your comment. These factors are described in greater detail within the full guideline

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		Foundation Trust				contributing specifically to the LD population developing mental health problems, as well as universal factors that apply to the general public e.g. lack of social participation, lack of autonomy, limited opportunities for work – is there evidence about this?	with references to the corresponding literature (section 2.5) which describes the correlatory evidence in this area which has included some of the factors that you list here. We would also expect that issues are ones that would be considered by those working directly with the person (see recommendations 1.8.5 and 1.8.6) and within a risk assessment (recommendations 1.8.18-1.8.20).
156	SH	Southern Health NHS Foundation Trust	Short	8	13	Reference to 'relevant manuals' - Would it be better to refer to interventions that are evidence based , Assessment Tools where possible should have been validated for use with people who have a learning disability and staff trained appropriately to use them.	Thank you for your comment. This wording was chosen as the evidence base in this population is limited, and to word this in this way may result in service users being denied interventions. We agree that tools should be validated and staff trained appropriately, and have stated this within recommendations 1.8.1 and 1.8.12.
157	SH	Southern Health NHS Foundation Trust	Short	8	17 19	Are there any specific outcome measures that NICE would recommend?	Thank you for your comment. The evidence base for assessment tools and outcome measures was reviewed. Few studies meeting our inclusion criteria were identified, and of those tools many had poor reliability and validity within our population, or were not practical in terms of time taken to administer. Therefore, on the basis of the reviewed evidence the GC were unable to recommend any specific tools. Please see section 4.5.2 of the full guideline for details of this review.
158	SH	Southern Health NHS	Short	8	20	Reference to Mental Health Assessment could suggest that	Thank you for your comment. The GC were confident that the heading would be clear to

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		Foundation Trust			22	there is one assessment. This doesn't reflect the range of areas that need to be considered and the variety of assessment tools that may need to be used. Would it be better to refer to Assessment of Mental Health Needs? Treatment is quite a medical term. Could this refer to Interventions?	clinicians and therefore will not be making this amendment.
159	SH	Southern Health NHS Foundation Trust	Short	9	1 21	There is a strong reliance here on verbal communication which can present significant challenges for people with a learning disability. Reference should also be made to non verbal factors that could inform the assessment of need e.g. physical appearance, changes in behaviour, cultural factors that may influence how symptoms are described and understood. Could more detail be added re: reasonable adjustments to accommodate sensory impairments e.g. sensory impairments range from physical disability re:sight / hearing impairments to complex conditions ADHD, Autism. Consideration should also be given	Thank you for your comment. The feedback received from our service users was that they are often spoken about rather than spoken to, and that they find this understandably distressing. It is for this reason that recommendation 1.3.1 precedes the sections on assessment and intervention. However, non-verbal factors and other sources of information potentially relevant to assessment can be found within section 1.8, and specifically within recommendations 1.8.1, 1.8.4, 1.8.6 and 1.8.7. Reasonable adjustments will vary depending upon the individual and their needs. Therefore the GC agreed that it would not be possible to provide a list of appropriate adjustments. Clinicians are expected to have the skills to make this judgement, as set out in 1.8.1 (assessment) and 1.9.2 (psychological interventions). Issues around engagement are dealt

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						in this section to working with people who are difficult to engage – what reasonable adjustments are required to support people to attend appointments / meetings?	with in section 1.3 (see recommendations 1.3.1-1.3.5).
160	SH	Southern Health NHS Foundation Trust	Short	12	8	If the term 'formulation' is used, should there be reference to some tentative explanatory hypotheses as well as description and intervention?	Thank you for your comment. The GC agreed that this level of detail was not necessary at this stage. The development of explanatory hypotheses and intervention plans is dealt with by recommendations 1.8.1-1.8.24.
161	SH	Southern Health NHS Foundation Trust	Short	13	4 6	It may not always be possible / appropriate to talk to the person on their own. Consideration should be given to the role of advocates in supporting people to raise concerns.	Thank you for your comment. We appreciate that there will be instances where it is not possible to speak to the person independently. However the GC were keen to ensure that this was the expectation, and to do otherwise should be the exception rather than the rule. Clinicians are expected to exercise judgement over the application of the recommendations. We agree that advocates may have a role to play in raising concerns.
162	SH	Southern Health NHS Foundation Trust	Short	13	16 28	These factors are also relevant to the Initial / Triage assessment.	Thank you for your comment. Whilst we agree that these factors are relevant in any assessment, we argue that they cannot be adequately excluded as reasons for distress without a full assessment. It is for this reason that this is mentioned at this point.
163	SH	Southern Health NHS Foundation Trust	Short	14	3	Whilst it is an important point to assess areas not necessarily mentioned by families, it is felt that it might set unrealistic expectations	Thank you for your comment. This section relates to further (comprehensive) assessment, which the GC agreed needed to be comprehensive. Brief assessments are covered within recommendation

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						to assert that 'all' potential psychopathology should be assessed in every mental health assessment. The wording may not acknowledge clinical judgement.	1.7.4.
164	SH	Southern Health NHS Foundation Trust	Short	14	19	Is it always appropriate to give a diagnosis using a formal classification system? Does this run the risk of over-pathologising clients?	Thank you for your comment. The GC agree that a diagnosis may not always be appropriate and it is for this reason that we list 'problem specification' as an alternative.
165	SH	Southern Health NHS Foundation Trust	Short	14	26	Would it be appropriate to advise that a risk assessment is always conducted?	Thank you for your comment. The GC did not feel that a risk assessment would always be needed, and that it would be more appropriate to advise that clinical judgement is used to decide whether or not to conduct a formal assessment of risk. They note that risk assessments are often treated as tick-box exercises, which do not contribute to good patient care, and can lead to an aversion to any risk which can have a detrimental effect on service user quality of life. They also agreed that the triggers to conduct a risk assessment are contained within the mental health assessment which should be updated as new information emerges.
166	SH	Southern Health NHS Foundation Trust	Short	14	28	Would it be appropriate to acknowledge that information about recent changes may also be available from the service user?	Thank you for your comment. The GC agree that relevant information should always be collected from the service user first, and that the assumption will be that to do otherwise will be the exception and not the rule. This is stipulated in a preceding

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							recommendation (revised recommendation number 1.8.1).
167	SH	Southern Health NHS Foundation Trust	Short	15	2	Formulations are often useful in a diagrammatical format. Would it be appropriate to acknowledge this here?	Thank you for your comment. The method that clinicians use to develop a formulation and communicate this is one of personal judgement, and this is more detail than is appropriate for a guideline.
168	SH	Southern Health NHS Foundation Trust	Short	15	18	Would be useful to acknowledge that a separate easy read version may be required for the service user i.e. the agreed format and language might be different for different people in the network? Consideration should also be given to issues relating to consent to share information.	Thank you for your comment. The need to provide information in an appropriate format is covered in recommendation 1.8.9, as well as within recommendation 1.3.1 which discusses principles of good communication
169	SH	Southern Health NHS Foundation Trust	Short	17	8	Should this also include a baseline assessment of cognitive functioning?	Thank you for your comment. The GC disagree with the view that a baseline cognitive assessment is required in addition to an assessment of adaptive function in this group. They agreed that this would require significant additional resources, and is not necessary to assist diagnosis of dementia. Therefore we will not be making this amendment.
170	SH	Southern Health NHS Foundation Trust	General	15	25	Reference is made to the Initial Assessment – how does this link with Triage?	Thank you for your comment. An initial assessment may be referred to as a triage assessment in some services.
171	SH	Southern	Short	17	21	Various additional factors around	Thank you for your comment. The GC agree that all

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		Health NHS Foundation Trust				risk to others prevalent in learning disabilities are not referenced here, including financial abuse, institutional abuse, familial abuse, 'mate crime', and radicalisation. Risk from others refers only to risk of exploitation and this felt to under-represent risk from others in this population.	of these are potentially important issues for people with learning disabilities and mental health problems. Safeguarding issues are covered earlier within the document in recommendation 1.8.2.
172	SH	Southern Health NHS Foundation Trust	Short	17	12 22	Risk of accident, suicide ideation, self harm are not mentioned.	Thank you for your comment. Risk of accident, self-harm and suicidal ideation are all encompassed by bullet point 1, which addresses 'risk to self'.
173	SH	Southern Health NHS Foundation Trust	General	17 18	26 1 26	How do Risk Management Plans link with Crisis or Contingency Plans within the CPA process? Important links could be made here with Models of Recovery.	Thank you for your comment. This is a local implementation issue and beyond our remit.
174	SH	Southern Health NHS Foundation Trust	Short	18	3	It is suggested that the risk management plan should also be shared with the service user where appropriate.	Thank you for your comment. The GC agree that any risk management plan should be developed alongside the service user and implemented with them (see recommendation 1.8.19-1.8.20). Within this context it would be confusing to state that the risk management plan should be shared with them, as it suggests that they may not have been involved in its' development.
175	SH	Southern Health NHS	Short	18	26	Would it be useful to explicitly reference CPA (Care Programme	Thank you for your comment. As the CPA specifically relates to secondary mental health

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		Foundation Trust				Approach) here?	services the GC decided that it would not be appropriate to reference the CPA here.
176	SH	Southern Health NHS Foundation Trust	Short	20	13	Would reference to use of the formulation in informing intervention be appropriate?	Thank you for your comment. The inclusion of formulation within the assessment is covered within recommendation 1.8.23.
177	SH	Southern Health NHS Foundation Trust	Short	21	20	Would it be useful to reference other ways in which CBT is adapted for this client group?	Thank you for your comment. The adaptations used will vary depending upon the needs of the client, therefore it was thought to be unhelpful to provide a list here.
178	SH	Southern Health NHS Foundation Trust	Short	22	18 23	How do you define Specialists with expertise in treating mental health problems. What is the role of GPs in prescribing? Where GPs do not the specialist knowledge is the expectation that referrals should be made to Psychiatry?	Thank you for your comment. Specialists could encompass a number of different professions who have specific training and experience with this population and will vary according to local service configurations, for example psychiatrists in learning disability or experienced non-medical prescribers. The GC discussed the role of GPs in prescribing and agreed that many GPs will feel capable, and be able to, prescribe if necessary with the exception of the two situations detailed within the recommendation. In these situations the expectation is that an onward referral will be made.
179	SH	Southern Health NHS Foundation Trust	Short	23	8 11	Further clarity re: the role of the Community Nurses would be helpful. What view does NICE have re: the role of Nurses in monitoring side effects of Mediation in liaison	Thank you for your comment. The wording of revised recommendation number 1.10.4 has been amended to more clearly delineate responsibilities and now reads 'assess whether support from community and learning disabilities nurses is needed for physical

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						with the Prescriber, In relation to support with having Blood tests, does NICE have a view on the use of clinical holding in exceptional circumstance where a person maybe need additional support and medication / desensitisation is not appropriate or hasn't been successful. Agreement re: monitoring responsibilities should be clearly linked to prescribing responsibilities.	investigations (such as blood tests)'.
180	SH	Southern Health NHS Foundation Trust	Short	24	9 13	The role of prevention needs to be considered much earlier in the document.	Thank you for your comment. We agree, and have now moved this section to the beginning of the document.
181	SH	Southern Health NHS Foundation Trust	Short	25	7-29	In addition to meaningful activities and employment it is important to consider the role of social support, social networks and meaningful relationships. When looking at roles and responsibilities around employment it is important for employers / job centres etc to have appropriate knowledge and expertise to support people with learning disability and mental health needs within the work place.	Thank you for your comment. The GC have stressed the importance of social support and involvement throughout the guideline, however specific mention is made in section 1.5.2. The need for employers to develop appropriate knowledge and expertise is covered within recommendation 1.11.4.

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182	SH	Southern Health NHS Foundation Trust	Short	25	21	Would it be appropriate to acknowledge some degree of choice for the service user regarding work, even if they are able?	Thank you for your comment, the GC have tried to convey this within the recommendation by the phrase 'work that is meaningful to them'
183	SH	Southern Health NHS Foundation Trust	Short	26	13	Would a hyperlink to the Equalities Act be useful when reasonable adjustments are mentioned?	Thank you for your comment. We have now added a hyperlink as suggested.
184	SH	Southern Health NHS Foundation Trust	Short	26	24 onwards	The definition given seems to be that of care co-ordinator. In many provider agencies, a 'key worker' refers to a named support worker. Is there a potential for confusion in terminology here?	Thank you for your comment. A number of different terms were discussed by the GC. The term key worker was decided upon as the least confusing option. The key worker role may be taken on by the care coordinator, a named support worker or another individual depending upon local service configurations.
185	SH	Southern Health NHS Foundation Trust	Short	27	15	Should the definition of severe LD come before profound LD, to avoid confusion?	Thank you for your comment. The glossary was organised alphabetically, which was why severe LD followed profound LD. The glossary terms have now been changed and now consist of 'learning disabilities' with 'milder' and 'more severe' as subheadings.
186	SH	Southern Health NHS Foundation Trust	Short	28	21	There has been a recent debate in local services regarding whether ADHD is a mental health problem or not. What is NICE's position on this?	Thank you for your comment. ADHD is classified as a neurodevelopmental disorder within this guideline.
187	SH	Southern	Short	31	23	Does this statement relate to	Thank you for your comment. Yes, this research

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		Health NHS Foundation Trust				people with LD, Anxiety and Autism, not just LD and Anxiety?	recommendation does apply to people with learning disabilities, autism and anxiety.
188	SH	Southern Health NHS Foundation Trust	Short	General	General	Would it be useful to make reference to the Greenlight Toolkit in terms of accessibility of mainstream Adult Mental Health Services?	Thank you for your comment. We are unable to recommend particular audit tools such as the Green Light toolkit unless we have reviewed high-quality evidence indicating that they are effective. Recommendation 1.2.2 has been altered to make explicit the duty of services to make reasonable adjustments and audit their services and now reads '…ensure that care is responsive to the needs and abilities of people with learning disabilities and that reasonable adjustments are made if needed, and regularly audited to assess accessibility and acceptability'. The principle of equal access is addressed within recommendation 1.2.5.
189	SH	Southern Health NHS Foundation Trust	Short	General	General	Question 2: The document often states that 'health and social care should…' One of the biggest challenges may be delineating which responsibilities relate to social care, and which to health, particularly when teams are co-located and not integrated.	Thank you for your comment. We agree that this is an important but potentially challenging area of practice. Local service configurations will vary and we expect commissioners to develop care pathways that address this issue (see recommendation 1.2.3).
190	SH	Southern Health NHS Foundation Trust	Short	General	General	What is NICE's position on the use of WRAP (Wellness Recovery Action Plans) in mental health Care Plans?	Thank you for your comment. We did not find any evidence that would have allowed us to recommend WRAP, however we appreciate that they could be of value. It is for local services to make a decision on

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							their utility.
191	SH	British Psychological Society	general	general	general	The Society welcomes these guidelines and would welcome the opportunity to work with NICE and other bodies to assist with implementation. We appreciate the view taken by the GC to consider adaptations that need to be made to psychological treatments developed for people without a learning disability so that such interventions can be delivered to people with learning disabilities; given that a limited quality evidence base does not necessarily mean that interventions with evidence in people without a learning disability will not be effective in people with learning disabilities, and that in taking such a stance, NICE have reduced potential for discrimination at a societal level that may exclude people with learning disabilities from accessing such psychological interventions. We also feel this	Thank you for your comments.

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						reflects the reality in which clinicians are operating, e.g. in needing to draw on assessment measures and interventions that have been developed in populations without learning disabilities, in their clinical work with people with learning disabilities. We also value that the guidelines' also highlight the paucity of research that there is concerning how best to treat mental health problems in people who have a learning disability; we welcome this and agree that the areas for further research that are highlighted at the end of the consultation are important.	
192	SH	British Psychological Society	general	General	General	The Society welcomes the principles of the recommendations made. We believe that a stronger statement could be made regarding this, particularly as part of the short version of the guidelines (which are	Thank you for your comment. It is not NICE editorial style to make statements about the limitations of the recommendations in the short guideline. Revised recommendation numbers 1.1.1 and 1.1.2 specifically directs readers to use this guideline in conjunction with NICE guidelines for people without learning disabilities.

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						most likely to be frequently accessed by clinicians) acknowledging the limitations of them, as well as directing readers to other NICE guidelines (i.e. for people without learning disabilities) where available.	
193	SH	British Psychological Society	Full	21	2.1.1	We believe that it would be helpful to include reference in the section on definitions and terminology of 'Learning disabilities' to the use of the term 'intellectual disabilities' in the academic literature, which is also used to refer to the same definition given to the label 'learning disabilities' to ensure this is clear for the remainder of the document (where the term 'intellectual disabilities' is sometimes used interchangeably / in reference to specific tools that use this label). Some members may prefer that the term 'intellectual disabilities' is used, given that this is now the preferred term in some services as well as academically; at least there should	Thank you for your comment. We have now added a sentence to make this clear and it now reads 'The term learning disabilities is synonymous with the term 'intellectual disabilities', used commonly within the academic literature.'

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						be a clear statement about rationale for choice of term by NICE and recognition of both terms being used in services.	
194	SH	British Psychological Society	general	general	general	The Society welcomes the reference within the draft guidelines to the NICE (2015) Challenging Behaviour and Learning Disabilities Guidelines. However, we thought that there could be a greater recognition / clearer statement in the guideline recommendations that people who challenge may also have mental health needs that need addressing, and that mental health problems for many individuals may be expressed / present / conceptualised as behaviour that challenges. It seemed that particularly in the short version of the guidelines, this message seemed lost. We are concerned that this may risk diagnostic overshadowing of people with learning disabilities who have mental health problems	Thank you for your comment. The points you raised have been addressed in the NICE (2015) Challenging Behaviour and Learning Disabilities Guideline and therefore are outside the scope of this guideline. Recommendation 1.1.1 refers to the challenging behaviour guideline and recommends that it is used alongside this guideline where appropriate. No evidence was reviewed for positive behavioural support, therefore we are unable to make specific recommendations for its' use.

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						which are labelled as 'challenging behaviour'. Additionally, it may be useful to make reference to the definition of Positive Behavioural Support, which makes it clear that a PBS plan may also include "The secondary use of other complimentary evidenced based approaches to support behaviour change at multiple levels of the system" (Gore et al, 2013). Complimentary approaches will include psychological therapies such as CBT, psychodynamic psychotherapy, Dialectical Behavioural Therapy, Cognitive analytic therapy etc., some of which are mentioned in the report but these links in the current NICE guidelines could be made more explicit in the recommendations.	
195	SH	British Psychological Society	general	General	General	The Society believes that the current NICE guidelines could helpfully be informed by the recent Joint report of Royal College of Psychiatrists and the Society on	Thank you for your comment. The guideline has received input from a number of the authors of this report, both as Guideline Committee members and as expert advisors.

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						psychological therapies (Beail, 2016) (available at: http://shop.bps.org.uk/publications/publications-by-subject/psychological-therapies-and-people-who-have-intellectual-disabilities.html)	
196	SH	British Psychological Society	general	General	General	The Society believes that reference should be made to access to mainstream mental health services, and reasonable adjustments that may need to be made by such services to ensure meaningful engagement of people with learning disabilities. Specifically, there should be reference to access to 'improving access to psychological therapies' (IAPT) services for people with learning disabilities, given that IAPT as mainstream psychological therapies services are so widely available (albeit in different service configurations) nationally, and the recent move to improve access to IAPT services for people with learning disabilities	Thank you for your comment. The variation in service configurations at a local level and increasing use of IAPT services by people with learning disabilities, particularly those at the milder end of the spectrum, were issues considered carefully by the Guideline Committee. Recommendation 1.9.2, for example, specifically cites remote delivery of psychological interventions as this is an option increasingly employed within IAPT services. Recommendation 1.8.1 meanwhile allows for the possibility that specialist services may provide consultation and supervision for non-specialist staff. This would include those in IAPT. However as decisions around service configuration are a local implementation issue, and beyond our remit, the Guideline Committee were reluctant to name specific service providers. Recommendations 1.2.5 (relating to organisation and service delivery), 1.2.10 (relating to staff training and supervision),

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						(e.g. Foundation for People with Learning Disabilities, 2015) and good practice guidance that people with learning disabilities should be entitled to access mainstream mental health services in addition to / with support of specialist learning disability services (e.g. Green Light Toolkit; National Development Team for inclusion, 2013). The reality of clinical practice is that many local specialist learning disability services are attempting to consider how to support their local IAPT (as well as other mental health services) to make reasonable adjustments and improve their access for people with learning disabilities and mental health problems such as depression or anxiety to receive CBT or other psychological interventions, and it would be helpful to have this referenced in the guidelines.	1.8.1 (relating to assessment) and 1.9.2 (relating to principles of delivering psychological interventions) do give guidance on the types of reasonable adjustment required by making it clear what competencies staff need to have in order to work with people with learning disabilities, the fact that assessments should be coordinated and supervised by those with appropriate specialist experience and adjustments that may need to be made for access to safe and effective delivery of care. The GC agreed that these principles apply irrespective of the particular service within which this takes place.
197	SH	British Psychologica	Short	6	30	The guidelines make reference to	Thank you for your comment. We recognise this is an issue, although investigation of the Hospital

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		l Society			31	acute inpatient treatment for people with learning disabilities and a serious mental illness, if needed. The Society has concerns about the challenges of implementing this recommendation for local inpatient provision, with clinicians reporting concerns about rapidly reducing availability of inpatient beds for people with learning disabilities, and a difficulty for people with learning disabilities accessing generic acute mental health inpatient facilities. There is also likely a scarcity of research investigating the experiences of service users or families accessing generic acute mental health inpatient facilities, and perhaps this may be helpful as a further recommendation for future research.	Episode Statistics (HES) dataset shows that these are small numbers of patients. This recommendation was made to address concerns raised, particularly by the carer representatives and through the service user focus groups, about the quality of care that they have received in these settings previously. The aim of this recommendation is to set standards to guide the reconfiguration of services, which has been identified by NHS England as a national priority. The evidence for different models of care was reviewed and was indeed found to be scarce. The GC agree that this is an area in which further research would be useful, but envisage that this would be one small qualitative aspect of a wider study, as per our 6th high-priority research recommendation which reads 'The experiences of people with learning disabilities and mental health problems within service systems'.
198	SH	British Psychologica l Society	short	7	1	In line with the Transforming Care agenda (NHS England, 2015), we believe that this paragraph should emphasise that any inpatient	Thank you for your comment. This guideline should be read alongside national policy documents such as 'Transforming Care'. The issues you describe are clearly set out within the Mental Health Act. Please see recommendation 1.8.21 which gives further

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						admission should be for the shortest time possible with a view to a safe, planned discharge at the earliest opportunity. We also have concerns that 'where possible' is too vague a term – it would be better to describe the exceptions to local provision – for example if a highly specialised national service is required.	detail on assessment during crisis. We are satisfied that the level of detail provided is adequate as local service configurations will vary, and the implementation of this guideline is beyond our remit.
199	SH	British Psychological Society	short	7	12 19	It would be helpful to have a recommendation on the basic competencies required for the key worker in terms of working with people with learning disabilities – for example specific communication training.	Thank you for your comment. The GC agreed that the recommendation as written provides an outline of the competencies that the key worker would need. For example without appropriate communication training one could not communicate in a manner suited to the person's needs. As a result we will not be making this amendment.
200	SH	British Psychological Society	Short	8	13	The Society has concerns about the emphasis on manualised care (i.e. that staff should "deliver interventions based on relevant manuals, if available") without reference to the rationale for this,	Thank you for your comment. This wording was chosen as the evidence base in this population is limited, and to word this in this way may result in service users being denied interventions.

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						which we assume is related to manualised interventions that have an evidence base i.e. this should be rephrased to reflect that staff should deliver "interventions based on manuals that reflect evidence based interventions, where available".	
201	SH	British Psychological Society	Short	8	17	We believe that there should be more explicit reference to possible options to be considered as routine sessional outcome measures, given the noted absence of quality evidence regarding the reliability / validity of these with this client group. There is also a potential impact for clinician time if completing sessional outcome measures; this can be time consuming particularly with this client group, given the limited availability of abbreviated measures (that are more likely to be validated in people without learning disabilities) and need for	Thank you for your comment. We accept that there may be variations in time taken. We expect that practitioners will not use outcome measures that are not relevant, and are best equipped to make this decision based upon the needs of the person they are working with. The GC agreed that a requirement to take these factors into account is adequate.

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						adaptations / considerations around communication needs and reasonable adjustments to use these with people with learning disabilities, and we feel there is not clear evidence for the benefit of completing sessional outcome measures (as opposed to outcome measures at discrete time-points throughout an intervention, to monitor progress and evaluation) given this increased time commitment. Perhaps it could also be made clear in the guideline where certain outcome measures may be indicated (e.g. directly administered outcome measures for individuals with less severe learning disability), versus indirect measures for those with more severe learning disabilities and limited language ability. On the basis of these points, this should perhaps be worded as: 'should consider using routine sessional or post-therapy outcome measures where measures	

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						appropriate to the client's level of learning disability are available.'	
202	SH	British Psychological Society	general	General	General	We believe that a reference to importance of patient reported experience measures should be included, and the need for these to be adapted for use with people with learning disabilities. For example, see case study by Roman Raczka and colleagues https://www.england.nhs.uk/wp-content/uploads/2014/10/elec-datcapt-paper.pdf and guidance by NHS England https://www.england.nhs.uk/ourwork/pe/fft/fft-inclusive/	Thank you for your comment. Service user reported measures have been added to revised recommendation number 1.2.11 and it now reads '…consider using routing sessional outcome measures including service user reported experience measures'. The expectation that tools or measures may need to be adapted is covered within revised recommendation number 1.8.12.
203	SH	British Psychological Society	Short	8	24	Regarding communication, we feel that there needs to be specific reference to working with people whose communication is severely impaired e.g. more severe learning disability, where clinicians will be working with the network but also capturing the service user's	Thank you for your comment. The need for the service user's perspective and preferences to be paramount throughout was felt by the GC to be exceptionally important. Additionally the feedback that we received from our service user focus group was that they are often talked about rather than being spoken to, and they find this understandably distressing. It is for this reason that the guideline stresses the need to address the service user

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						perspective. We recommend including something to the effect of "where communication is severely impaired, for example with people with very severe or profound learning disabilities, consideration should still be given to involving and capturing the perspective of the person with a learning disability, in consultation with the network of people that know them well'	themselves (see recommendation 1.3.1). We believe that the scenario you describe, however, is captured by the requirement in recommendation 1.8.1 and 1.8.3 (assessment) and 1.9.3 (psychological interventions) to involve and work with family members or carers, as appropriate.
204	SH	British Psychological Society	short	General	General	We believe that much of the guidelines (particularly apparent in short version) appears to be written for people working with less severe learning disabilities. There appears to be an assumption throughout that the mental health team will be able to communicate directly with the person with the learning disability, whereas good mental health work with people with severe difficulties is often on a partnership with / consultation to the network. There is a danger by not explicitly stating the additional	Thank you for your comments. Whilst the GC were aware throughout the development process of the need to address the specific difficulties faced when working with individuals with more severe learning disabilities, the lack of good quality evidence prevented us from producing many specific evidence-based recommendations for this group. In an effort to address this we have prioritised research in those with severe to profound learning disabilities. We disagree however that the guideline applies only to those with milder learning disabilities; for example the intervention section on social and environmental adaptations (1.5.1 and particularly 1.5.2) was developed through informal consensus and written with those with more severe learning disabilities in

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						accommodations needed for people with more severe impairments then their needs will continue to not be met.	mind, 1.7.1 gives indications of behavioural changes indicating mental health problems in those who are non-verbal and 1.3.4-1.3.5 stress the need to involve the network as much as possible. Additionally of the 3 specific psychological interventions listed, 2 are based upon work in service users with more severe learning disabilities. They are not identified as being useful only in those with a more severe learning disability as the GC agreed that these may be useful for those with a milder learning disability as well. Additionally, the GC were mindful of the need to balance practicalities with the right of the service user to be involved as much as possible in all aspects of their care. The approach taken (and language used throughout) was intended to try and balance these two priorities.
205	SH	British Psychological Society	Short	9	23	The guidance should consider the issues of consent; capacity and decision-making within secure/ forensic settings that may differ to a community or voluntary context (please also see later comments at the end of this document regarding potential further guidelines	Thank you for your comment. The GC agree that these are important considerations. Mental health assessment and intervention for those within the criminal justice system is the subject of a separate NICE guideline currently in development, which is due to publish in February 2017.

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						regarding secure / forensic settings).	
206	SH	British Psychological Society	short	11	1 10	When referencing support available to family members we think specific reference should be made to advising them of their right to a carer's assessment should be made. There is reference to 'a formal assessment of their own needs (including their physical and mental health)' however we believe that highlighting this as a 'carer's assessment' is in line with clinical / social care practice.	Thank you, the wording of the recommendations has been amended in line with your comment and revised recommendation number 1.4.1 now reads: 'advise family members and carers about their right to the following and how to get them; a formal assessment of their own needs [commonly referred to as a 'carer's assessment]'.
207	SH	British Psychological Society	short	12	14	The Society recommends that this is changed from 'Refer people….. to a psychiatrist with expertise…' to 'Refer people…. to the relevant pathway so they can access expertise in the assessment and treatment of mental health problems in people with learning disabilities'. This reflects that there are variations in how services are	Thank you for your comment. We have now altered the wording of the recommendation (revised number 1.7.5) and it now reads 'refer people with learning disabilities who have a suspected serious mental illness…'. The GC agreed that access to a review by a psychiatrist would often be necessary in this situation.

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						configured locally and referral to a psychiatrist, rather than another clinician with appropriate experience, may not be the first action. In addition, the Society is aware that good practice guidance would advise multidisciplinary assessment and intervention e.g. in dementia (British Psychological Society & Royal College of Psychiatrists, 2015). We are concerned that the message regarding the importance of multidisciplinary working may be lost if there is reference to one discipline only.	
208	SH	British Psychological Society	Short	12	17	Throughout section 1.6 on Assessment, there is a concerning lack of reference to consideration of individuals' cultural background in developing an understanding of their mental health difficulties or their family systems understanding of mental health / illness, despite the recognised need for understanding of cultural factors	Thank you for your comment. Recommendation 1.8.6 has been amended in line with your suggestion and bullet point 4 now reads 'take into account the person's cultural, ethnic and religious background'.

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						(e.g. Faculty of the Psychiatry of Learning Disability of the Royal College of Psychiatrists, 2011).	
209	SH	British Psychological Society	Short	13	4 6	We believe this section needs more careful consideration of communication needs (e.g. where individual may not be able to independently communicate verbally), cognitive style (e.g. autism) and previous trauma history here. At the very least insert this sentence may need to start with 'where appropriate' and explain that if this is not possible then other means of assessing these risks will be needed.	Thank you for your comment. We believe that these points are covered earlier within the document in section 1.3 on involving the person and others, as well as recommendation 1.8.7 which discusses the use of other informants and sources of information.
210	SH	British Psychological Society	Short	8	17	We believe that there should be more explicit reference to possible options to be considered as routine sessional outcome measures, given the noted absence of quality evidence regarding the reliability / validity of these with this client group.	Thank you for your comment. We accept that there may be variations in time taken. We expect that practitioners will not use outcome measures that are not relevant, and are best equipped to make this decision based upon the needs of the person they are working with. We believe that a requirement to take these factors into account is adequate.

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						There is also a potential impact for clinician time if completing sessional outcome measures; this can be time consuming particularly with this client group, given the limited availability of abbreviated measures (that are more likely to be validated in people without learning disabilities) and need for adaptations / considerations around communication needs and reasonable adjustments to use these with people with learning disabilities, and we feel there is not clear evidence for the benefit of completing sessional outcome measures (as opposed to outcome measures at discrete time-points throughout an intervention, to monitor progress and evaluation) given this increased time commitment. Perhaps it could also be made clear in the guideline where certain outcome measures may be indicated (e.g. directly administered outcome measures for individuals with less severe	

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						learning disability), versus indirect measures for those with more severe learning disabilities and limited language ability. On the basis of these points, this should perhaps be worded as: 'should consider using routine sessional or post-therapy outcome measures where measures appropriate to the client's level of learning disability are available.'	
211	SH	British Psychological Society	general	General	General	We believe that a reference to importance of patient reported experience measures should be included, and the need for these to be adapted for use with people with learning disabilities. For example, see case study by Roman Raczka and colleagues https://www.england.nhs.uk/wp-content/uploads/2014/10/elec-datcapt-paper.pdf and guidance by NHS England https://www.england.nhs.uk/ourwork/pe/fft/fft-inclusive/	Thank you for your comment. Service user reported measures have been added to revised recommendation number 1.2.11 and it now reads '…consider using routing sessional outcome measures including service user reported experience measures'. The expectation that tools or measures may need to be adapted is covered within revised recommendation number 1.8.12.

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212	SH	British Psychological Society	Short	8	24	Regarding communication, we feel that there needs to be specific reference to working with people whose communication is severely impaired e.g. more severe learning disability, where clinicians will be working with the network but also capturing the service user's perspective. We recommend including something to the effect of "where communication is severely impaired, for example with people with very severe or profound learning disabilities, consideration should still be given to involving and capturing the perspective of the person with a learning disability, in consultation with the network of people that know them well'	Thank you for your comment. The need for the service user's perspective and preferences to be paramount throughout was exceptionally important for the GC. Additionally the feedback that we received from our service user focus group was that they are often talked about rather than being spoken to, and they find this understandably distressing. It is for this reason that the guideline stresses the need to address the service user themselves (see recommendation 1.3.1). We believe that the scenario you describe, however, is captured by the requirement in recommendation 1.8.1 and 1.8.3 (assessment) and 1.9.3 (psychological interventions) to involve and work with family members or carers, as appropriate.
213	SH	British Psychological Society	short	General	General	We believe that much of the guidelines (particularly apparent in short version) appears to be written for people working with less severe learning disabilities. There appears	Thank you for your comments. Whilst the GC were aware throughout the development process of the need to address the specific difficulties faced when working with individuals with more severe learning disabilities, the lack of good quality evidence prevented us from producing many specific

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						to be an assumption throughout that the mental health team will be able to communicate directly with the person with the learning disability, whereas good mental health work with people with severe difficulties is often on a partnership with / consultation to the network. There is a danger by not explicitly stating the additional accommodations needed for people with more severe impairments then their needs will continue to not be met.	evidence-based recommendations for this group. In an effort to address this we have prioritised research in those with severe to profound learning disabilities. We disagree however that the guideline applies only to those with milder learning disabilities; for example the intervention section on social and environmental adaptations (1.5.1 and particularly 1.5.2) was developed through informal consensus and written with those with more severe learning disabilities in mind, 1.7.1 gives indications of behavioural changes indicating mental health problems in those who are non-verbal and 1.3.4-1.3.5 stress the need to involve the network as much as possible. Additionally of the 3 specific psychological interventions listed, 2 are based upon work in service users with more severe learning disabilities. They are not identified as being useful only in those with a more severe learning disability as the GC agreed that these may be useful for those with a milder learning disability as well. The GC were mindful of the need to balance practicalities with the right of the service user to be involved as much as possible in all aspects of their care. The approach taken (and language used throughout) was intended to try and balance these

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							two priorities.
214	SH	British Psychological Society	Short	16	20	The guideline makes reference to the Glasgow Depression Scale, but neither the short nor full version of the guideline appears to make reference to the Glasgow Anxiety Scale, and we were not sure if this was an omission or if the scale did not meet NICE criteria for inclusion. In reality of clinical practice, this is a frequently used tool for assessing anxiety in people with learning disabilities.	Thank you for your comment. No high quality evidence was found for the use of the Glasgow Anxiety Scale, and therefore the GC could not recommend this tool.
215	SH	British Psychological Society	Short	17	5	The Society believes that there are a number of other potential assessment tools to support assessment of dementia in people with learning disabilities, as outlined in other good practice guidance (e.g. British Psychological Society & Royal College of Psychiatrists, 2015) which are frequently used in clinical practice (such as the CAMCOG / CAMDEX), are not contained in the	Thank you for your comment. The evidence for tools appropriate for use in people with learning disabilities (including for the assessment of dementia) was reviewed. This included the CAMCOG and CAMDEX. The tools listed in the recommendations were the only ones of sufficient quality to merit recommendation by the GC. The CAMCOG and CAMDEX were found to have significant limitations within this population, including substantial evidence of floor effects. Please see section 4.5.2 of the full guideline for details of this review.

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						NICE guidelines, although we recognise that this may be as they did not meet NICE criteria for inclusion.	
216	SH	British Psychological Society	short	17	7	The Society believes that this recommendation could not be implemented in many services for people with intellectual disabilities without sufficient additional resources. We would therefore like to see this reflected in the wording of the recommendation (example below). The Society also thinks that if a baseline assessment is being completed for all adults who are receiving care form a service, this should include a cognitive assessment as well as an assessment of adaptive behaviour, as recommended in professional good practice guidance (British Psychological Society & Royal College of Psychiatrists, 2015): "Specialist learning disabilities services should be commissioned	Thank you for your comment. The GC disagree with the view that a baseline cognitive assessment is required in addition to an assessment of adaptive function in this group. They asserted that this would require significant additional resources, and is not necessary to assist diagnosis of dementia. As it is good practice for the information needed for assessments of adaptive function to be contained within the care record the GC disagree with the view that this in itself would require additional resources, and instead are of the view that this recommendation merely formalises and supports what should already exist. We have made this clearer within the relevant 'Linking Evidence to Recommendations' section of the full guideline (section 4.6). We will not be making the proposed amendment to the recommendations.

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						in a way that enables designated practitioners to complete baseline assessments of cognitive functioning and adaptive behaviour with all adults with Down's syndrome who are receiving care from the service" If there is a clear rationale for NICE recommending conducting only adaptive behaviour assessment in this situation (rather than including cognitive assessments in addition), this should be clearly stated in the short guidelines / recommendations.	
217	SH	British Psychological Society	Short	18	1	Further guidance on communicating risk / care plans to the service user themselves may wish to be considered.	Thank you for your comment. The GC agree that risk and care plans should be developed in collaboration with and communicated clearly to the service user. The need to do this is set out in recommendation 1.8.20, 1.8.22 and 1.8.24.
218	SH	British Psychological Society	short	21	1	The Society recommends that that the person's understanding of emotions and labels for emotions is assessed, as this is a precursor to	Thank you for your comment. The GC agree that this is important. This is covered within revised recommendation number 1.9.3. The GC were concerned that to state this earlier within this section may result in service users being denied access to

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						them being able to express or describe emotions. For example, a first bullet point could be added as follows: "Assess the person's understanding of emotions and labels for different emotions."	interventions, and therefore the current placement of this point was the most appropriate.
219	SH	British Psychological Society	Short	21	7	Section 1.8.3 refers to exploring how 'progress will be measured and how data will be collected' in order to evaluate psychological interventions. Additional guidance about the suitability and use of psychometric measures with this population would be beneficial at this point in the guideline. It would also be useful to have some guidance on additional methods to assess progress.	Thank you for your comment. The use of appropriate outcome tools is covered within recommendations 1.8.12-1.8.16. This has not been repeated here in order to avoid duplication.
220	SH	British Psychological Society	Short	21	18	Consideration to the use of mindfulness as a possible intervention with this population may also be valuable. This does	Thank you for your comment. We agree that further, good-quality, research on the use of a wider range of psychological interventions within this population is needed. The GC decided however that in the context of the very limited evidence base that this is too

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						not seem to be referenced in the short or the full version of the guideline in relation to being an intervention for people with learning disabilities themselves. The evidence for employing this method with Learning Disabled service users is fairly limited, and this may be why it has not been included in the guideline, but the approach does seem to be used in Learning Disability settings. Perhaps this could be considered as an area for future research to further explore its effectiveness.	specific a topic to be a high priority research recommendation.
221	SH	British Psychological Society	Short	21	27	The guidelines recommend considering parent training to help prevent or treat mental health problems in the child. From reading the evidence it appears that all of the studies included looked at groups that had been run for parents whose children had behavioural difficulties, e.g. ADHD, Oppositional defiance disorder, serious behaviour problems. Given	Thank you for your comment. Given that mental health problems can present as challenging behaviours within this population, the GC decided that it was appropriate to extrapolate the findings from the evidence reviewed for the challenging behaviour guideline. We have now added to the rationale presented in the full guideline to point out that such programmes appear to have some positive impact upon carers as well as children. Given the high levels of stress that can be associated with caring for a child with disabilities and the effect that parent mental health problems can have on the

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						this, we question how the group can then recommend this intervention for the prevention or treatment of mental health problems as such problems were not targeted by the parent training programmes.	child, the GC agreed that this was also good reason to recommend parent training to assist in the prevention of mental health problems.
222	SH	British Psychological Society	Short	22	11	The Society welcomes that psychological interventions are privileged ahead of pharmacological interventions in the guidelines in terms of order of presentation, however we feel that there should be a more explicit statement in the short guidelines where it may be appropriate to consider psychological interventions before or at least alongside pharmacological interventions, and that pharmacological interventions should never be considered in isolation but alongside other psychosocial interventions.	Thank you for your comment. This is covered earlier in the guideline as it relates to overarching principles of collaborative care and good communication. It can be found within the sections on involving people with learning disabilities (1.3.1-1.3.3) and their carers or family members (1.3.4-1.3.5). As per the recommendations in section 1.3 information should be provided in the most appropriate format, and decisions made in collaboration with the person, and the clinician should be sufficiently competent to achieve this.
223	SH	British Psychologica	Short	24	26 onwards	Following Winterbourne View, we	Thank you for your comment. The GC agree that these are both important points and have therefore

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		l Society				feel there should be a clear statement about reducing the use of out of family / out of area placements by providing appropriate local support and respite wherever possible.	recommended using locally available services as much as possible in recommendation 1.2.6 and offering respite care in recommendation 1.4.1.
224	SH	British Psychologica l Society	Short	25	7	The guideline has helpful section on occupational interventions; however it was not clear whether Occupational Therapists have been involved in developing the guideline or in consultation on the draft. We also thought there was lacking a mention of sensory processing work, although appreciate this may be due to a limitation in evidence base. Again, we hope that this may be something that can be usefully commented on by Occupational Therapy as part of the consultation process.	Thank you for your comment. We did not have an occupational therapist on the GC. Any interested parties are able to register as stakeholders. Registered stakeholder organisations, which include NHS trusts, will include staff working as occupational therapists. No evidence was found relating to sensory processing work and therefore we are unable to recommend this.
225	SH	British Psychologica l Society	Short	26 27		The Society has concerns about the use of the terms 'mild', 'moderate', 'profound' and 'severe' learning disabilities, seemingly	Thank you for your comment. IQ was a key inclusion criteria for the reviews conducted for this guideline. This was a practical choice as many studies, particularly older studies, include participants upon the basis of their IQ score. To do otherwise would

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						made predominately on the basis of IQ level. Please see BPS (2015) which elaborates on this concern that 'The Society endorses the view that there is generally little to be gained from sub-classifying persons with intellectual disability on the basis of IQ alone' (page 15), 'however, it recognises that there may be occasions when it is appropriate to distinguish between levels of intellectual disability' (page 15), but that when this is done, that this should be done on the basis of both intelligence and adaptive behaviour, and that this distinction should be made between 'intellectual disability' and 'severe intellectual disability' rather than use of 'mild / moderate / severe / profound' learning disability. The Society therefore recommends that NICE consider this in its use of terminology and definitions in this document.	have resulted in an already sparse evidence base being further reduced. However the GC agree with the point made here, and we have now amended the wording used in the short guideline to 'milder' and 'more severe', with adaptive behaviour clearly included within these definitions. Where the evidence is discussed and studies defined specific groups sub-classifications have been used for transparency.
226	SH	British	Short	27	6		Thank you for your comment. The terminology has

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		Psychological Society				We are concerned that the description of a person with a "mild" learning disability being in paid employment is misleading and should be amended to read "may be able to work in paid employment". It is our clinical experience that many people with even "mild" learning disabilities struggle significantly with sustaining paid employment even with support, and there may also be broader societal issues in the current employment climate that may make it difficult for individuals to gain and sustain paid employment.	been amended and a definition of 'milder' learning disabilities has been introduced, with the suggested alteration to the description of adaptive abilities. The definition of 'milder' learning disabilities now reads '*people with milder learning disabilities may be able to live independently and care for themselves, managing everyday tasks and working in paid employment, can often communicate their needs and wishes, may have some language skills, may have needs that are not clear to people who do not know them well'.*
227	SH	British Psychological Society	Short	General	General	Although the guideline primarily focuses on Mental health and Learning Disability, it may be useful to have some reference to the comorbidity between "Personality Disorder" and Mental Health within this client group. Specifically, guidance on the suitability of Personality Disorder assessment	Thank you for your comments. Personality disorders were included in the list of conditions that fell within our scope. Unfortunately, despite comprehensively reviewing the evidence, no assessment tools for personality disorders with adequate sensitivity and specificity were identified for this group. Therefore the GC were unable to make any recommendations in this area.

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						measures for this group would be valuable.	
228	SH	British Psychological Society	Short	General	General	Additional guidance specifically for service users within secure settings (custodial and mental health) would be useful. Further guidance concerning social and physical environment (page 24) and involving family members, carers and key workers (page 10) within the constraints of secure settings would be beneficial. Interventions Services (IS) within the National Offender Management Service (NOMS) has developed a number of interventions for service users who have offended and considered as Borderline to Mild Learning Disabled. The service is tasked with keeping abreast of research concerning this population with the aim of developing evidence-based interventions within community and custodial settings. Continual evaluation of the	Thank you for your comments. Mental health assessment and intervention for those within the criminal justice system is the subject of a separate guideline currently in development, which is due to publish in February 2017.

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						intervention programmes for this population is also undertaken by IS and as such may be well placed to contribute to the guidelines.	
229	SH	British Psychological Society	Short	General	General	**References** Beail, N. (2016). Psychological therapies and people who have intellectual disabilities. Leicester: British Psychological Society. British Psychological Society (2015). Guidance on the Assessment and Diagnosis of Intellectual Disabilities in Adulthood. Leicester: British Psychological Society. British Psychological Society & Royal College of Psychiatrists (2015). Dementia and People with Intellectual Disabilities Guidance on the assessment, diagnosis, interventions and support of people with intellectual disabilities who develop dementia. Leicester: British Psychological	Thank you for these references. They do not meet our criteria for inclusion in this guideline.

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						Society. Emerson, E. (2005). Use of the Strengths and Difficulties Questionnaire to assess the mental health needs of children and adolescents with intellectual disabilities. Journal of Intellectual and Developmental Disability, 30, 1–10. Emerson, E. and Baines, S. (2010) The estimated prevalence of autism among adults with learning disabilities in England. Stockton-on-Tees: Improving Health and Lives Faculty of the Psychiatry of Learning Disability of the Royal College of Psychiatrists (2011). Minority ethnic communities and specialist learning disability services. Faculty of the Psychiatry of Learning Disability of the Royal College of Psychiatrists Foundation for People with Learning Disabilities (2015).	

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						Learning Disabilities: Positive practice guide. London: Foundation for People with Learning Disabilities. Gore et al. (2013). Definition and scope for positive behavioural support. International Journal of Positive Behaviour Support, 3 (2), 14-23. National Development Team for inclusion (2013). Green Light Toolkit 2013: A guide to auditing and improving your mental health services so that it is effective in supporting people with autism and people with learning disabilities. Bath: NDTi NHS England (2015). Building the Right Support: A national plan to develop community services and close inpatient facilities for people with a learning disability and / or autism who display behaviour that challenges, including those with a mental health condition.	

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						https://www.england.nhs.uk/wp-content/uploads/2015/10/ld-nat-imp-plan-oct15.pdf Perlman, L. (2000). Adults with asperger disorder misdiagnosed as schizophrenic. Professional Psychology: Research and Practice, 31(2), 221-225. Rossiter, R., Armstrong, H., Morgan, S., & Phillips, N. (2013). Same or different? Measuring outcomes in children and young people with learning disabilities, their families and networks. Child and Family Clinical Psychology Review, 1, 84–92.	
230	SH	Mental Health Foundation	Full	General	General	The Mental Health Foundation, which incorporates the Foundation for People with Learning Disabilities, is pleased to have the opportunity to respond to this consultation. As an organisation focused on mental health and wellbeing, our response will emphasize the rights foundation underpinning the care and support	Thank you for your comments.

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						required for those with learning disabilities who experience mental health challenges; how the person's individual needs should be central to their care plan; and detail the merits of shifting the focus of the debate from reactive care to prevention and supporting the mental wellbeing of the person. When it comes to supporting those with learning disabilities who experience mental health problems, the priority has to be ensuring their care plans are tailored to the individuals need, placing the person at the centre of care. That said, it is vital that the debate is shifted up-stream to begin to tackle the root causes of mental ill-health and understand how services can be shaped more effectively to manage and support wellbeing and prevent poor mental health. Identifying the most vulnerable needs to be a priority here; getting the right structures in place to really get to know the individuals and	

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						their needs and from this, be able to identify early warning signs to support early intervention when needed. Only with dedicated funding for prevention can the Government start to tackle the increasing prevalence of mental health problems in our society. Getting services right for those with learning disabilities involves rethinking our approach to mental health by supporting people at the right time; this would offer us the opportunity to save lives and prevent unnecessary distress as well as reaping substantial economic and social benefits. Some of the recommendations we will make have direct cost implications however this, we argue, will be offset by the mid to long term economic merits of keeping an individual mentally healthy so as avoiding pressure across already stretched public services.	

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						The recommendations we make are evidence based and champion the individual. As it stands, there are a number of structures in place to support those with learning disabilities and mental health problems but the real issue we wish to flag with our comments is that there is nothing in place to enforce these structures and ensure the required support is provided in the way it should be. With nothing to enforce change, failures in care happen and those who need support are allowed to slip through the structures in place.	
231	SH	Mental Health Foundation	Full	General	General	What is missing from the consultation? • We are concerned that the consultation does not make recommendations around an adequate flagging system for those with learning disabilities. We argue that both screening and triage areas need to be improved upon, looking to	Thank you for your comments. The identification of learning disabilities, whilst an important issue, is beyond the scope of this guideline. We agree that access to services is an issue nationally, and that early intervention is highly desirable (such as the 'fast response team' and 'fast stream' ideas that you raise). However, service configurations and access to those services are local implementation issues and again are beyond the scope of this guideline.

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						the '3 question' recommendation in Improving Access to Psychological Therapies (IAPT) Learning Disability Positive Practice Guide. This system would facilitate a more thorough screening process and subsequent flagging process for those with learning disabilities. • We would like to make the recommendation that should those awaiting diagnosis and/or treatment who are moved between different practitioners, or are referred to different specialists, should not have to re-join the waiting list to access the next step in their treatment and support. We argue there should be a fast stream service setup for those moving around within the health service and that each healthcare professional and individual	Thank you for your comments on the equalities act and its implementation. Thank you for your comments relating to staff training. Whilst recommendations 1.2.9 and 1.2.10 attempt to set basic standards for safe care, our expectation is that clinicians will develop a more in-depth understanding of the people with whom they specifically work. Recommendations 1.3.1 and 1.8.6 relate specifically to developing an understanding of the person and their needs. Consistency of support was a concern raised by both our service user group and members of the Guideline Committee. This is, in part, a staff retention issue and beyond the scope of the guideline. However recommendation 1.2.9 is designed to ensure that staff know the circumstances in which to make an onward referral and to whom this should be. Parity of esteem was also raised as an issue throughout the guideline development process and we have begun to try and address this with our recommendations on the inclusion of mental health in annual health checks (Section 1.6).

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						comes across has a sufficient understanding of the fast-stream system and what should be prioritised for the individual. • We recommend that a fast response team around the person is deployed at the first point of referral. If the best support is offered at the first point of contact, and those involved in caring for the individual were included from the outset, the need for more costly services could be prevented. • For the Mental Health Foundation, a central motivation for responding to the consultation is to stress that the Equalities Act is legally binding; it is not something that can be applied to a situation when it suits, rather forms the foundation of all service provision and support. As a	

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						result of its central position to service delivery for those with learning disabilities, any changes or increases to costs will be reflective of need, and therefore justified. The question to start from should be "what does the individual need and how can services best support this" as opposed to being led by cost; if the latter has the power to dictate the former, the individual will cease to be at the centre of their care pathway. • We argue that education and training for health practitioners across the board needs to be central to the recommendations made by the consultation. When it comes to learning disabilities, there is no such thing as a one-size-fits-all approach; training to support one individual does	

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						not automatically translate to knowing the right care and support plan for another and this message needs to be stressed throughout the consultation. Training for health professionals needs to be bespoke, placing the care needs of the individual in question at the centre of the process. As it stands, the recommendations do call for training/education however the wording is such that the personalised nature of the training required is lost on the reader. • It should be stressed that while a friendly ear from care staff is to be desired, there needs to be a greater degree of consistency of support for those with learning disabilities who experience mental health challenges. Triggers for the	

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						individual need to be understood and exactly how this should be escalated upwards to the appropriate specialist. • People who have mental health problems including anxiety and depression do not receive such prompt and comprehensive care as they do for physical health conditions, and timely access to mental health services is even worse for people with learning disabilities. We call for a commitment to parity of esteem for physical and mental health and this must be introduced for the whole population. This call should be reflected in The Five Year Forward View for Mental Health. Recommendations from the new strategy should apply equally to those with, and those without, learning	

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						disabilities.	
232	SH	Mental Health Foundation	Short	6	25	We argue that this recommendation should mention the inclusion of mainstream services when it comes to access. The person should be referred to the best practitioner irrespective of whether they are specialist or mainstream.	Thank you for your comment. We agree that people should be referred to the most appropriate service for their needs. It is for this reason that recommendation 1.2.5 requires access to all NICE-recommended interventions for mental health problems, which may well be provided within services such as Increasing Access to Psychological Therapies (IAPT) depending upon local service configurations.
233	SH	Mental Health Foundation	Short	7	1	Here is it important to stress that this recommendation needs to have a broader focus and should refer to mainstream or specialist staff, or both where relevant. Training needs to be tailored to the individual to shape a unique care plan to fit specific needs, especially when this relates to severe learning disabilities or those individuals who present behaviours that challenge. There should be an expectation for treatment plans to be adhered to and supported by care staff.	Thank you for your comment. We agree that inpatient admissions could be within either a mainstream or specialist setting. The recommendation requires that all involved staff should have the knowledge and skills necessary to manage mental health problems in people with learning disabilities. Recommendation 1.2.10 further addresses the necessary competencies to be able to do this.
234	SH	Mental Health Foundation	Short	8	20	Involving people with learning disabilities, and their family members, carers or care workers	Thank you for your comment. Clinicians are expected to exercise judgement over who from within the service user's support network may

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						are vital and relevant to supporting an individual going through mental health assessment and treatment. In many cases it would be difficult to identify which one of the three would be best as for many cases, a joint effort would be best suited as support networks are varied and integrated. So what does this 'involvement' look like? • The individual should be at the centre of all plans with their wishes and opinions listened to and understood. • A circle of support that includes families, carers and/or relevant healthcare team member that keeps the persons wishes at the centre of all decisions and ensures that the person remains in their community. • We would like an individual's full support network to be thoroughly	appropriately be involved. The GC agreed that it would not be appropriate to impose a blanket rule that does not account for each individual's circumstances and preferences. Similarly, each individual is different and has different support needs. The GC did not agree that an MDT response is required for every single individual. The aim of NICE guidelines is to set standards of good practice. Unfortunately the implementation of these is beyond our remit. Behaviour support plans are beyond the scope of this guideline, and are covered within the NICE guideline on Challenging Behaviour in Learning Disabilities.

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						briefed on their care plan. With this knowledge, they will then also have the opportunity to feed into the care plan should they identify areas that need building on. The individualised care plan is an excellent idea however as it stands, its lack of enforcement detracts away from its potential to involve a variety of people in the care and support of the individual in question and ultimate recovery or ability to cope with life. We would like this to be consistently enforced and monitored. We would like to see commissioners enforcing care and support plans/Behaviour Support Plans more broadly across all areas of the UK engaging a variety of care professionals. The costs associated with bringing this in would be likely to be offset by the long term savings this approach	

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						presents. Particularly where more costly interventions or placements a long way from home become an exception rather than the rule. Finally, we would like a multidisciplinary team to be involved from the outset. This has the benefit of creating truly personalised care and ensuring the individual has a good knowledge of who they will be supported by moving forward and what this care will look like. Should a multidisciplinary team be involved from the outset of the intervention, it is more likely that mental health challenges could be prevented as well as preventing the deterioration of the individuals health and ultimately meaning that more expensive and extensive services being required. Our work at the Foundation for People with Learning Disabilities has highlighted that people with learning disabilities have either a	

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						reduced or no concept of mental health nor do they see themselves as candidates for mental health support (candidacy). We are working with people with learning disabilities to develop their role as consultant expert by experience in delivering wellbeing awareness sessions with people with Learning disabilities using our Feeling Down Guide. This includes developing an understanding of what is mental health and developing a wellbeing plan.	
235	SH	Mental Health Foundation	Short	10	17	We would like to see the word 'encourage' removed from this recommendation and replaced with 'train'. Family members, carers and care workers must be involved from the outset to understand what the individuals needs are so this training needs to be obligatory as opposed to desired, as the recommendation currently suggests.	Thank you for your comment. The GC discussed this issue at length and the need to balance the rights and wishes of both service users and their families and carers, in addition to relevant legislation. We are concerned that the removal of the word 'encourage' also removes this balance and therefore we will not be making this amendment.
236	SH	Mental	Short	11	28	The Mental Health Foundation	Thank you for your comment. We hope that the

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		Health Foundation				would like to see a more specific focus here on the role of GPs in identifying common mental health problems in people with learning disabilities. GPs are, for the most part, the first point of contact for many seeking care and support and we argue that the training currently available to GPs to support those with learning disabilities is lacking. As it stands, we would consider the current set up as the first point of failure in the system. Our consultation with People with learning disabilities, families and staff is detailed in our report, Feeling Down, highlights a number of recommendations that we believe should be included in the recommendations moving forward. Please find these recommendations below: 1. Commissioners should ensure that service providers demonstrate compliance with the Equality Act	requirement for mental health to be included in annual health checks will address this issue in part (see section 1.6). We also refer to other guidelines where specific advice is provided (rec 1.1.1) as well as advice on modifications of assessment for individuals with learning disabilities (section 1.8). Thank you for drawing our attention to your recommendations. The GC considered these issues carefully (see section on pathways, recs 1.2.1-1.2.6) and on the basis of their expert opinion made relevant recommendations

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						and the Mental Capacity Act through regular audits to be shared with the local Health and Wellbeing Boards and CCGs. 2. Each CCG should appoint a specialist learning disabilities clinical lead to advise and act as champion for the needs of people with learning disabilities, as well as maintain a link with the NHS England learning disability clinical lead. 3. Professional bodies responsible for education and training should introduce compulsory modules on learning disability for all health professionals including psychiatrists, GPs and psychotherapists in training posts. Practitioners should be required to gain experience in working with people with learning disabilities, regardless of their chosen speciality, with teaching being partly delivered by people with learning disabilities. 4. General practices should ensure	

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						they have identified all people with learning disabilities on their register and offer appropriate health checks (which include mental health) and health action plans through regular audits to be shared with the local Health and Wellbeing Boards and CCGs. 5. NHS England should audit the roll-out of inclusive national mental health programmes such as Improving Access to Psychological Therapies (IAPT), dementia screening and information prescriptions, checking that they are delivering inclusive services. 6. Service providers should implement the Michael inquiry recommendations in mental health trusts as well as in acute hospitals and primary care. 7. Directors of social services should require health and social care commissioners to ensure that all individuals receive personalised care and support in appropriate community settings as soon as possible. (The Winterbourne action	

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						plan stated that detailed personal plans for the return of all out of borough placements should be drawn up and presented to district and borough councils for approval by June 2014. Councils are to report to NHS England on progress by July.) 8. NHS England, working in conjunction with local commissioners, should prepare detailed plans setting out how specialist learning disability services are to provide prompt and effective liaison and facilitation services, with special emphasis on delivering communication support and identifying appropriate adjustments, to support people with learning disabilities or autism to fully access a service. 9. The CQC should require the chief inspectors of hospitals, of primary care and of social services to include questions about reasonable adjustments and barriers to the provision of inclusive services in all of their inspections	

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						(on the basis that people with learning disabilities should have access to all services, not just specialist services).	
237	SH	Mental Health Foundation	Short	12	6	We would like to see the use of the word 'staff' in this recommendation changed to 'trained staff'. To be able to provide the individualised care plans that are required for people with learning disabilities who experience mental health challenges, training has to be thorough and flexible and the recommendations need to be very clear as to which members of staff are providing the care. When it comes to triage assessment, we would like to see the staff in question referred to in a more specific fashion which highlights the level of training they require to carry this out appropriately. We also recommend that a clear understanding of the social model of disability and compassion should be essential elements in the curriculum.	Thank you for your comment. We agree that it is important that staff are adequately equipped by their employer to do their job to the best of their ability. We expect that service providers will provide such training, as per recommendations 1.2.9 and 1.2.10. A number of different staff groups could be capable of conducting triage assessments. It is for local services to determine which staff, within their service structure, are appropriately placed to do this. We expect that all staff will operate within the boundaries of their competence.

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238	SH	Mental Health Foundation	Short	13	16	We would argue a fourth point needs to be added to the list of recommendations of areas to be aware of. We think that medication that has the capacity to impact changes needs to be included.	Thank you for your comment. The GC agree that this is an important point. This recommendation relates to diagnostic overshadowing, however the impact of medication is addressed within recommendation 1.8.6.
239	SH	Mental Health Foundation	Short	15	1	We would like to use this recommendation to stress the meaning of an individualised care plan, and exactly how this will be effectively communicated to staff. Our message for GPs is that mental health and wellbeing is included in the health action plan. We would like to see a central communications strategy put in place here across all CCGs to highlight, especially to GPs as the first point of contact, what care plans can look like and how best they can and should be tailored to the specific needs of the person experiencing mental health challenges.	Thank you for your comment. The GC agree that unless they are tailored to the needs of the person for whom they are intended, that care plans cannot be effective. The points you raise are dealt with as far as possible within recommendations 1.8.22-1.8.24. Implementation is a local issue and beyond our remit.
240	SH	Mental	Short	18	28	We would like to see a GP	Thank you for your comment, this would be beyond

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		Health Foundation				instruction pack produced to inform and guide GPs on what to be aware of and how to shape an effective health action plan that includes mental health and wellbeing.	the remit of NICE guidelines.
241	SH	Mental Health Foundation	Short	19	12	Annual health checks should include wellbeing plans/mental health with the central aim of this being to shift the care focus towards prevention as opposed to reaction. A review on the quality of health checks should be undertaken and guidance that they should include wellbeing and mental health. The Learning Disabilities Mortality Review suggests that people with learning disabilities are still dying earlier than the general population from preventable illnesses.	Thank you for your comment. The GC agree that annual health checks should include mental health and feel that this is captured within recommendation 1.6.3. The section on annual health checks has been moved to earlier in the document in order to emphasise their preventative nature.
242	SH	Mental Health Foundation	Short	21	23	This recommendation could directly refer to mindfulness which could be included in addition to relaxation therapy. Mindfulness has been successfully used in Improving	Thank you for your comment. The list of specific psychological interventions reflects the available evidence. No good quality evidence was found to allow the GC to recommend any psychological interventions other than those listed.

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						Access to Psychological Therapies (IAPT) services along with CBT. Also by specialists where it was found to support people to manage anxiety. From our work in improving access to Improving Access to Psychological Therapies (IAPT) we found Improving Access to Psychological Therapies (IAPT) and Community Learning Disability Team (CLDT) practitioners, in Surrey and Borders Partnership NHS Foundation Trust, had worked together to deliver mindfulness groups for people with learning disabilities which yielded positive results.	
243	SH	Mental Health Foundation	Short	24	9	We call for the inclusion of those with learning disabilities in the creation of wellbeing plans (highlighted earlier in our response) outlining clearly what mental health means for those with learning disabilities and how wellbeing can best be supported. More literature is needed here as general levels of understanding here are far lower	Thank you for your comment. The GC agree that there is a real dearth of literature relating to mental health in people with learning disabilities, and how best to support wellbeing. We have made a number of research recommendations which we hope will address this issue.

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						than they should be to be able to shape a truly preventative agenda.	
244	SH	Mental Health Foundation	Short	24	11	Any time care plans are mentioned it is important that the word 'individualised' is used. As it stands, the recommendations remain too vague without this word and it detracts from what should be the central motivation for these recommendations to be made; that those with learning disabilities are all individuals and their care should reflect this.	Thank you for your comment. As care plans should always be individualised we will not be making this amendment.
245	SH	Mencap	Short	7 8	General	In the staff training and supervision section it would be helpful to include a reference to offering staff training or support to access information about the nature of services available and training for staff to have skills to support the person to access interventions.	Thank you for your comment. The GC agree that it is important that staff know where to signpost and how to support access to interventions, and this is already covered within recommendation 1.2.9.
246	SH	Mencap	Short	12	1.6	In the section on conducting a mental health assessment it could be clearer how this methodology works for people with profound and multiple learning disabilities, who	Thank you for your comment. The GC agree that this is an important consideration, and that this is covered within a preceding recommendation (1.3.1) addressing communication needs.

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						mostly won't use formal communication such as words and signs.	
247	SH	Mencap	Short	15	1.6.8	When talking about the adjustments needed to deliver the interventions this could be linked back to any agreed support offered to staff to have the skills to support this. It also may be useful to identify any restrictions that the intervention may lead to.	Thank you for your comment. The GC agree that an integrated approach is important and have tried to capture this issue in the recommendations related to delivery and staff training (recs 1.2.9-1.2.10).
248	SH	Mencap	Short	16	1.6.12	We are not sure 'consider' is strong enough. If there are reliable tools that have been developed with people with learning disabilities in mind would they not be the preferred tools.	Thank you for your comment, the use of the word 'consider' relates directly to the strength of the evidence. The evidence was not a sufficient quality in this area for a direct or stronger recommendation
249	SH	Mencap	Short	17	1.6.18	It needs to be clear how people identify and access these practitioners.	Thank you for your comment. Practitioners could refer to a range of different people such as carers, support workers, GPs or mental health or social care staff.
250	SH	Mencap	Short	21	1.8	The list of specific psychological interventions is quite short. Does it match the list of interventions that are recommended for people without a learning disability (for example the use of mindfulness)?	Thank you for your comment. The list of specific psychological interventions reflects the available evidence. No good quality evidence was found to allow the GC to recommend any psychological interventions other than those listed.
251	SH	Mencap	Short	23	1.9.7	There could be more on the	Thank you for your comment. We agree that over-

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						potential difficulties that people face in medication changes, but it also needs a stronger statement about people who are using antipsychotics with no psychosis. Using the words 'consider' and 'annually document' do not seem a very strong description. See NHS England urgent action pledged on over-medication of people with learning disabilities: https://www.england.nhs.uk/2015/07/urgent-pledge/	medication is an issue of grave concern. The GC have tried to strike a balance here between ending the practice of leaving people on drugs that they may no longer need, and not suddenly removing them from everyone, including those who may still need them. As this section was developed through formal consensus, this is the strongest description that we are able to provide.
252	SH	Mencap	Short	25	1.11.1	It would be helpful to have a much wider description of what 'access local resources, such as those provided at day centres' means.	Thank you for your comment. We have now amended revised recommendation number 1.11.1 in a manner which we hope is clearer. It now reads '…access local community resources, such as libraries, cinemas, café's and leisure centres'.
253	SH	Mencap	Short	25	1.11.2	This should include reference to support to find a job and support to maintain a job, which some people may need.	Thank you for your comment. These considerations are dealt with comprehensively within recommendations 1.11.3 and 1.11.4.
254	SH	Mencap	Short	General	General	There needs to be a description of what this means for assessment taken on an inpatient basis and how this connects to community provision.	Thank you for your comment, as we were unsure which section of the guideline you are referring to we are unable to give a comprehensive response. However, we note that following Winterbourne view people with learning disabilities are being moved from long-term inpatient care into the community,

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							and therefore it was not deemed to be appropriate to provide recommendations for this setting. The needs of those with serious mental illness have been addressed (see recommendation 1.2.6 for explicit reference).
255	SH	Mencap	Short	General	General	It would be helpful if there was a more explicit description of who will coordinate all of this, for example, the role of the CPA.	Thank you for your comment. The GC noted that CPA is implemented differently across the country and is specific to secondary MH services, therefore they agreed that it would be unhelpful to reference it. Care coordination is the subject of section 1.2 of the short guideline
256	SH	Partnerships In Care	Short	12	13	Apart from psychosis and dementia, Bipolar Disorders and Severe Depressions with psychotic features also need to be evaluated by the psychiatrists. Psychosis may be a part of these conditions and it might be helpful to specify this. Clinical presentations of these conditions in people with LD can be complex and need specialist assessments. We need to keep in mind that people with LD are more at risk of suffering from mental illnesses.	Thank you for your comment. The wording of this recommendation (revised number 1.7.5) has been amended to refer to 'serious mental illness' to encompass the wider group of conditions to which you refer.

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257	SH	Partnerships In Care	Short	14	19	For people with mild ID, ICD & DSM are quite adequate.	Thank you for your comment. This recommendation has been amended to include the ICD and DSM-5 and the 6th bullet point of revised recommendation number 1.8.6 now reads *'review physical health and any current medication and refer to other specialists for review if needed'*.
258	SH	Partnerships In Care	Short	16	12	Mini PASAD is helpful as a screening tool but probably unnecessary if a full clinical assessment is carried out by a specialist trained in diagnosing mental illness in LD.	Thank you for your comment. We have now removed the mini PAS-ADD from this recommendation.
259	SH	Partnerships In Care	Short	23	29	As per another NICE Guidance, antipsychotics are recommended in treatment of bipolar disorder. It would be helpful to clarify that psychosis can be part of clinical presentation of bipolar disorder or depression with psychosis.	Thank you for your comment. The wording of revised recommendation number 1.10.8 has been altered for clarity and now reads 'for people with learning disabilities who are taking antipsychotic drugs and not experiencing psychotic symptoms'.
260	SH	Partnerships In Care	Short	21	general	The guidance re: psychological interventions should probably be more general rather than mention only depression and anxiety – ie, consideration for specific interventions for mental illness	Thank you for your comment. The recommendations reflect the available evidence. Whilst evidence of sufficient quality was available for the use of CBT in depression and anxiety, no such evidence was available for its use in other conditions

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						(including depression, anxiety, psychosis, etc) could all be covered by CBT (or adapted version of this)	
273	SH	Action on Hearing Loss	Short	General		Action on Hearing Loss is the charity formerly known as RNID. Our vision is of a world where deafness, hearing loss and tinnitus do not limit or label people and where people value and look after their hearing. We help people confronting deafness, tinnitus and hearing loss to live the life they choose. We enable them to take control of their lives and remove the barriers in their way. We give people support and care; develop technology and treatments and campaign for equality. Our response will focus on key issues that relate to people with hearing loss. Throughout this response we use the term 'people with hearing loss' to refer to people with all levels of hearing loss, including people who are profoundly deaf. We are happy for	Thank you for your comments. The wording of recommendation 1.3.1 has now been altered to specify both visual and hearing impairments as common considerations when communicating with someone who has a learning disability and mental health problem, in response to your comments and now reads 'make adjustments to accommodate sensory impairments (including sight and hearing impairments)'. The GC agreed that the requirement for staff to be trained to be able to make appropriate adjustments for such impairments is made clear within this recommendation.

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						the details of this response to be made public. Action on Hearing Loss supports the broad aims of this guideline to improve the prevention, assessment and management of mental health problems in people with learning disabilities. Diagnosing and managing hearing loss, and taking hearing loss into account when diagnosing and managing mental health problems is crucial for good communication and care. Evidence suggests that levels of hearing loss are much higher in people with learning disabilities compared to than the general population. Around 40% of people with learning disabilities have hearing loss and this is often undiagnosed or misdiagnosed[1]. People with hearing loss have an increased risk of mental health problems and there is good	

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						evidence that hearing aids reduce these risks. Without hearing aids, people with hearing loss will struggle to communicate with friends, family and health and social care professionals and will be at greater risk of worse care and poor health. Some people with profound levels of hearing loss may use British Sign Language (BSL) as their main language and may require specialist care and support. The commissioning of mental health and social care services does not always take account of the unique communication needs of people who use BSL. **<u>Background</u>** There are 11 million people with hearing loss, about one in six of the population[2]. Hearing loss is caused by a number of factors which could include regular and prolonged	

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						exposure to loud sounds, ototoxic drugs, genetic predisposition or complications from injuries or other health conditions. Age related damage to the cochlear is the single biggest 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 with hearing loss. There are also an estimated 900,000 people in the UK with severe or profound hearing loss. Some people with severe or profound hearing loss may use British Sign Language (BSL) as their main language and may consider themselves part of the Deaf Community, with a shared history language and culture.	

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						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[4]. Hearing loss has been shown to have a negative impact on overall health – and this is likely to be exacerbated when people have learning disabilities as well. 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[5]. Hearing loss has also been	

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						associated with more frequent falls[6], diabetes[7], stroke[8] and sight loss[9]. Evidence suggests people with learning disabilities are more likely to develop hearing loss earlier compared to the general population and are at greater risk of associated health problems[i]. 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[ii]. Hearing loss has been shown to have a negative impact on overall health. Studies have found that hearing loss is independently associated with increased use of health services, an increased burden of disease amongst adults	

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						and an increased risk of mortality[10].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[11]. There is strong evidence of link between hearing loss and dementia.[12]. Research shows that hearing loss can also be misdiagnosed as dementia or make the symptoms of dementia appear worse[13]. **<u>Diagnosis and treatment</u>** Hearing aids improve quality of life[14] and help people with hearing loss communicate, stay socially	

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						active and reduce the risk of loneliness and depression[15]. New evidence suggests they may even reduce the risk of dementia[16]. However, many people are waiting too long to get their hearing tested. Research shows that people wait on average ten years before seeking help for their hearing loss and hearing aids are most effective when fitted early[17]. People with learning disabilities may find it difficult to report their hearing loss due to communication difficulties, which can often lead misdiagnosis and ineffective treatment[18]. There are currently no national screening programmes for hearing loss, including for people with learning disabilities. People with learning disabilities may also need additional support to get the most	

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						out of their hearing aids. Evidence suggests that 70% of people with learning disabilities have be seen by audiologist but only 24% receive on-going assessments and hearing aid maintenance[19]. Every person with learning disabilities, and everyone who needs hearing aids should get on-going adjustments and support – these are proven to increase hearing aid use and improve communication. **Access to Health** People with learning difficulties may face additional communication challenges when accessing health and social care services due to their hearing loss, which may lead to confusion over diagnosis and ineffective care. Our *Access All Areas*[20] research shows after attending an appointment with their GP, more than a quarter of survey	

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						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 GPs followed simple communication tips, this could improve understanding and make treatment more effective. People with hearing aids may also benefit from hearing loop systems, yet over a third (35%) said these weren't available. The situation is even worse for people who use BSL. Research by the *Our Health in Your Hands* campaign[21] shows more than two thirds (68%) of survey respondents who asked for a sign language	

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						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. Research by the charity Signhealth[22] also suggests that people who use BSL are at risk of poor health due to inaccessible public health information. Over a third (34%) of people who use BSL who had a health assessment were unaware they had high or very high blood pressure, and of those who had already had a diagnosis of hypertension, around two thirds (62%) had high blood pressure compared to a fifth (20%) of the general population. **Mental health services for people who use BSL** People with learning disabilities who use BSL may need specialist mental health services that take	

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						account of unique language and culture of the Deaf community. A systematic review[23] of the literature on mental health and deafness shows that people who have severe or profoundly levels of hearing loss have an increased risk of mental health problems. Standard tests and mental health measures may be ineffective if people with who use BSL are unable to communicate well in English. The review also shows that people who use BSL value specialist mental health services that use medically skilled BSL interpreters. Guidance issued by the Department of Health suggests that more need to be done to improve the provision of specialist mental health services for people who use BSL, as the current level of provision suggests a high level of unmet need[24].	

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						Recommendations In general, the Mental health problems in people with learning disabilities guideline must make reference to the following: 1. <u>The relationship between hearing loss and mental health</u> People with hearing loss have increased risk of mental health problems such as anxiety and depression and there is good evidence that hearing aids reduce these risks (see above). Given the high prevalence of hearing loss in people with learning disabilities and their increased risk of poor health, health and social care practitioners should be alert to the symptoms of hearing loss and be aware of role of the GP in referring people for a hearing test, in line with the NICE quality standard for Mental	

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						wellbeing of older people in care homes[25]. 2. <u>The need for specialist care and support for people who use BSL</u> People with learning disabilities who use BSL may need specialist mental health services that enable them to communicate well and receive effective mental health treatment. In addition, people with learning disabilities who use BSL may also need culturally sensitive adult social care and support. Adult social care services must meet their requirements under the Equality Act 2010 not to discriminate against people with protected characteristics and must consider the appropriateness of care and support services for people who use BSL.This includes the provision of a qualified BSL interpreter and also support to help	

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						people who use BSL communicate well and participate in local community, for example by supporting people to attend local Deaf clubs or other community groups. When arranging adult social care for people with learning disabilities who use BSL, health and social care practitioners should use specialist planning tools to make sure people who use BSL have choice and control over how their care is provided. To find out more, please visit https://www.actiononhearingloss.org.uk/supporting-you/care-and-support/person-centred-working/person-centred-tools.aspx 3. NHS England's Accessible Information Standard. NHS England's Accessible Information Standard[26] provides clear guidance on what NHS providers and providers of publicly	

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						funded health and social care must do to make their services accessible for people with hearing loss. The standard establishes a clear framework to make sure people with sensory loss and learning disabilities, including people with hearing loss, can communicate well and understand information they are given. We welcome the reference to the Accessible Information section 1.3.1 of this guideline. However, as well as providing information in additional formats such as Easy Read, people with learning disabilities who also have hearing loss may need additional forms of support to communicate well. Staff involved in mental health assessments and treatment of people with hearing loss should follow simple communication tips such as speaking clearly and making sure people who lipread are able to read their lip movements and communication support such as hearing loop or qualified BSL	

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						interpreter should be provided to all those who need it. It's vital that all NHS and adult social providers have processes in place meet the standard's requirements to identify and record the communication and information needs of people who use services, and share these with other services where appropriate. **Questions** 1. Do any recommendations represent a substantial increase in costs, and do you consider that the reasons given in the guideline are sufficient to justify this? 2. Which areas will have the biggest impact on practice and be challenging to implement? Please say for whom and why. The recommendations on "communication" (section 1.3.1) should ensure people with hearing loss are fully involved in	

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						discussions about their care. We welcome the inclusion of "sensory impairments" in the list of considerations when communicating with people with learning disabilities, as well as the references to NHS England's Accessible Information Standard[27]. The standard provides clear guidance on what health and social care services should do to make their services accessible for people with sensory loss and learning disabilities, including people with hearing loss. If the guideline is to be effective, the standard must be properly implemented and enforced. As stated in the specification for the Accessible Information Standard this includes the provision of staff training and internal communications to raise awareness of the standard's requirements. The standard has the potential to significantly improve the	

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						experience of people with sensory loss and learning disabilities who use health and social care services. NHS and adult social care providers must have the necessary resources and training to implement the standard in full. The recommendations on "identification and referral" (section 1.5) will also require staff training to make sure staff are alert to the alert to the early signs of mental health problems and associated health conditions. As stated above, Evidence suggests people with learning disabilities are more likely to develop hearing loss earlier compared to the general population and are at greater risk of worse health – including mental health problems. 3. What would help users overcome any challenges? (For example, existing practical resources or national initiatives, or examples of good practice.)	

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						Action on Hearing loss has produced guidance for GPs on making their services accessible for hearing loss. This includes on information and advice on making waiting areas and consultation rooms accessible for people with hearing loss and also guidance on the different types of communication support people with hearing loss may need to communicate well during appointments. To find out more please visit https://www.actiononhearingloss.org.uk/supporting-you/when-you-need-to-see-a-gp/guidance-for-gps.aspx Action on Hearing Loss has produced guidance on what hospitals can do to make their services accessible for people with hearing loss, which also provides valuable tips for improving communication across all health settings. The *Caring for Older*	

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						People with Hearing Loss project found that simple steps such as hearing screening, staff training and the provision of hearing aid maintenance kits and listening equipment on hospital wards improved communication between hospital staff and patients. To find out more, please visit www.actiononhearingloss.org.uk/nursingtoolkit	
274	SH	Action on Hearing Loss	Short	5	19 25	We welcome the inclusion of these points in the guideline. When organising care, the designated leadership team must consider the different forms of support people with hearing loss may need to get the most out mental health services. People with hearing loss have an increased risk of mental health problems such as anxiety and depression. Hearing aids can help reduce these risks, but many people are waiting too long to get their hearing tested. People who use British Sign Language (BSL) may need specialist services that take account of the unique	Thank you for your comment. Recommendation 1.2.2 has now been altered to make clearer the need for services to make reasonable adjustments (which includes those required to accommodate sensory impairments) so that people with learning disabilities and mental health problems are able to access the appropriate services. It now reads 'The designated leadership team should ensure that care is…responsive to the needs and abilities of people with learning disabilities and that reasonable adjustments are made if needed and regularly audited to assess effectiveness, accessibility and acceptability'

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						language and culture of the Deaf community (for more information and a full list of references, please see comment 1). Ensuring services are "accessible and acceptable" as stated in section 1.2.2. of this guideline is also particularly relevant for people with learning disabilities who may face additional barriers to communication when local accessing health and social care services due to their hearing loss. Our research shows that people with hearing loss may struggle to contact local health and social care services when they need to and may find it difficult to understand what is being said in the consultation room, due to poor deaf awareness of the lack of communication support. Without a highly qualified communication professional, people who use BSL in particular are at risk of worse care and poor health[iiiiv] (for more information and a full list of	

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						references, please see comment 1). The designated leadership team must ensure care pathways support the implementation of NHS England's Accessible Information Standard[v]. The third bullet point should be reworded to include a requirement to support the implementation of the standard. For example, "are accessible and acceptable to people using services – in line with NHS England's Accessible Information Standard".	
275	SH	Action on Hearing Loss	Short	6	5 11	We welcome this recommendation to share information with other services. The recommendation should reference NHS England's Accessible Information Standard[28], which states that information on communication and information needs must be shared with services as part of routine referral, discharge and handover processes, in line with data protection requirements.	Thank you for your comment. We agree that information sharing is an important area of practice. Information sharing should always be according to local policies and procedures including Caldicott principles, and in accordance with the Data Protection Act. We expect that with this population that information on sensory needs would be included if appropriate.

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276	SH	Action on Hearing Loss	Short	6	14 15	We welcome this recommendation to establish clear links with other care pathways. This recommendation should be reworded to include a reference to the hearing loss referral pathway for assessment and treatment, given the high prevalence of hearing loss and greater risk of associated health problems in people with learning disabilities. People with hearing loss have an increased risk of mental health problems such as anxiety and depression[vi]. Hearing aids can help people communicate with friends, family and health and social care processionals', and also help people manage their own health. There is also good evidence that hearing aids reduce the risk of mental health problems[vii]. However, evidence suggests that people wait on average ten years before seeking help for their hearing loss. Early diagnosis is crucial to make sure people with hearing loss get the most out of their hearing aids.	Thank you for your comment. We agree that many people with learning disabilities will experience sensory impairments, including hearing loss. Recommendation 1.3.1 has been amended to include hearing loss specifically and now reads '…make adjustments to accommodate sensory impairments (including sight and hearing impairments)'. The hearing loss referral pathway, however, relates to physical health and is beyond the scope of this guideline.

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						Hearing aids are most effective when fitted early and people with severe or profound hearing loss find it more difficult to adapt to hearing aids[viii]. Awareness of early signs of hearing loss and early diagnosis and treatment is especially important for people with learning disabilities who may find it difficult to report their hearing loss due to communication difficulties[ix].	
277	SH	Action on Hearing Loss	Short	7	9 10	We support the recommendation that staff working with people with learning disabilities should be aware of "other physical health problems". This recommendation should be expanded to include "sensory loss". Diagnosing and managing hearing loss and taking hearing loss into account when diagnosing and managing other conditions is crucial for good communication and care[x]. Evidence suggests people with learning disabilities are more likely to develop hearing loss and its associated health problems earlier compared to the general	Thank you for your comment. The wording of recommendation 1.2.7 has been altered to explicitly mention sensory impairments and now reads '…the nature and severity of the mental health problem, and any physical health problems (including sensory impairments'.

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						population, but this often goes undiagnosed or is misdiagnosed[xi].	
278	SH	Action on Hearing Loss	Short	9	6	We welcome this recommendation to "make adjustments to accommodate sensory impairments". The guideline should reference NHS England's Accessible Information Standard[xii] at this point as it also provides clear guidance on what health and social care services must do to make their services accessible for people with hearing loss. This recommendation should also be reworded to give examples of adjustments that may benefit people with hearing loss. For example, these could include: • Good deaf awareness – staff should follow simple communicate tips such speaking clearly and not obscuring lip movements with hand gestures or other objects (this is particularly beneficial for people who lipread). • Hearing loop systems – people	Thank you for your comment. The GC agreed that this is a level of detail beyond that expected of a guideline. We maintain that the need for staff to be able to work with those with sensory impairments (including hearing loss) is made clear within recommendation 1.2.7, and that staff working with people with learning disabilities will be familiar with some of the helpful adjustments that can be made to assist those with sensory impairments to access services. Recommendation 1.3.1 has been amended to include specific references to hearing loss, signing and the accessible information standard and now reads '…make adjustments to accommodate sensory impairments [including sight and hearing impairments]…use different methods and formats for communication [written, signing, visual, verbal or a combination of these] depending on the person's preferences [see the accessible information standard for guidance on ensuring people with learning disabilities receive information in formats they can understand]'. NICE guidelines do not make reference to policy documents, such as the NHS England document

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						who wear hearing aids may benefit from a hearing loop system that improves speech clarity by reducing the level of background noise. • Communication professionals – people with hearing loss may need support from communication professionals such as BSL interpreters, Lipspeakers, Speech-To-Text-Reporters or Notetakers.	you refer to, as it is a guideline based on the clinical evidence reviewed.
279	SH	Action on Hearing Loss	Short	11	24 27	Recommendation 1.5.1. should make reference to the importance of diagnosing hearing loss in preventing deterioration in mental health and wellbeing. Family members and carers should be aware of the link between hearing loss and poor mental health and the importance of hearing aids in reducing these risks. Early diagnosis is crucial to make sure people with hearing loss get the most out of their hearing aids (for more information and a full list of references, please see comment 4).	Thank you for your comment. Whilst we agree that hearing impairment is a common complaint in people with learning disabilities, diagnosis of hearing loss is a physical health concern rather than mental health, and as such is beyond the scope of this guideline. The GC agreed that the need to consider physical health as a possible cause for apparent mental health problems is covered within recommendation 1.8.4 which refers to diagnostic overshadowing.

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280	SH	Action on Hearing Loss	Short	13	17 20	Given the high prevalence of hearing loss in people with learning disabilities[xiii], professionals conducting mental health assessments should be aware of the links between hearing loss and mental health problems (for more information and a full list of references, please see comment 4), the links between hearing loss and dementia and also how hearing loss may mask underlying health problems. Evidence suggests that people with hearing loss have an increased risk of dementia[xiv]. People with mild hearing loss have double the risk of developing dementia, with moderate hearing loss leading to three times the risk, and severe hearing loss leading two five times the risk[xv]. New evidences suggests that hearing aids may reduce the risk of dementia[xvi].Hearing loss can also be misdiagnosed as dementia or make the symptoms of dementia appear worse[xvii].	Thank you for your comment. The GC agree that professionals working with this group should be aware of the high prevalence of sensory impairments, including hearing loss, and how to appropriately accommodate these. The requirement for staff to have these skills is set out within recommendations 1.2.7 and 1.3.1. Additionally we have now amended revised recommendation number 1.8.4 to mention sensory impairment and the second bullet now reads 'that a physical health condition, sensory or cognitive impairment may mask an underlying mental health problem'
281	SH	Action on	Short	19	15	We welcome this recommendation	Thank you for your comment. Hearing loss is

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		Hearing Loss			17	to include assessments of "conditions and impairments which are common in people with learning disabilities" in annual health checks. We recommend adding another sentence to this recommendation to make sure GPs are screening people with learning disabilities for hearing loss. Around 40% of people with learning disabilities have some level of hearing loss, which is often undiagnosed or misdiagnosed[29]. Early diagnosis is crucial to make sure people with hearing loss can communicate well and get the most out of their hearing aids (for more information and a full list of references, please see comment 4).	covered by the statement that you have highlighted within this recommendation (revised recommendation number 1.7.3).
282	SH	Action on Hearing Loss	Short	20	17 18	We support the inclusion of "sensory impairments and communication needs" in the list of considerations for delivering psychological interventions. People	Thank you for your comment.

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						with learning disabilities may need additional support to communicate well during appointments and understand written information due to their hearing loss (for more information, please see comment 6). People who use BSL may require specialist mental health interventions that take account of the unique language and culture of the Deaf community (for more information, please see comment 1).	
283	SH	Action on Hearing Loss	Short	General	General	[1] Kiani R and Miller H (2010) Sensory impairment and intellectual disability Advances in psychiatric treatment. 16, 228–235; Foundation for people with learning disabilities, 2015. Hearing Loss. Available from: http://www.learningdisabilities.org.uk/help-information/learning-disability-a-z/h/hearing-loss/ [2] Action on Hearing Loss (2015) Hearing matters. Available at: www.actiononhearingloss.org.uk/hearingmatters [3] Davis (1995) Hearing in adults.	Thank you for these references

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						London: Whurr [4]Chisholm et al (2007) A systematic review of health-related quality of life and hearing aids: Final report of the American Academy of Audiology task force on the health-related quality of life benefits of amplification in adults. *Journal of American Academy of Audiology*, 18, 151-183; Ciorba et al (2012) The impact of hearing loss on quality of life of elderly adults. *Clinical interventions in aging*, 7,159-63; Dalton et al (2003) the impact of hearing loss on quality of life in older adults. *The Gerontologist*, 43 (5) ,661-68; Mulrow et al (1990) Quality-of-life changes and hearing impairment, a randomized trial. *Annals of Internal Medicine,* 113 (3), 188-194. [5] Appollonio et al (1996) Effects of sensory aids on the quality of life and mortality of elderly people: A multivariate analysis. *Age and Ageing*, 25, 89-96; Genther et al (2013) Association of hearing loss with hospitalization and burden of	

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						disease in older adults. *Journal of the American Medical Association*, 309 (22), 2322; Karpa et al (2010) Associations between hearing impairment and mortality risk in older persons: the Blue Mountains Hearing Study. *Annals of Epidemiology*, 20 (6), 452-9. [6] Lin and Ferrucci (2012) Hearing loss and falls among older adults in the United States. *Archives of internal medicine*, 172 4, 369-371. [7] Kakarlapudi et al (2003) The effect of diabetes on sensorineural hearing loss. *Otology and Neurotology*, 24 (3), 382-386; Mitchell et al (2009) Relationship of Type 2 diabetes to the prevalence, incidence and progression of age-related hearing loss. *Diabetic Medicine*, 26(5), 483-8; Chasens et al (2010) Reducing a barrier to diabetes education: identifying hearing loss in patients with diabetes. *Diabetes Education*, 36 (6), 956-64. [8] Formby et al (1987) Hearing loss	

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						among stroke patients. Ear and Hearing, 8 (6), 326-32; Gopinath et al (2009) Association between age-related hearing loss and stroke in an older population. *Stroke*, 40 (4), 1496–1498. [9] Chia et al (2006) Association between vision and hearing impairments and their combined effects on quality of life. *Archives of Ophthalmology*, 124 (10), 1465-70. [10] Kiani R and Miller H (2010) Sensory impairment and intellectual disability Advances in psychiatric treatment. 16, 228–235. [11] Hétu et al (1993) The impact of acquired hearing loss on intimate relationships: implications for rehabilitation. *Audiology*, 32 (3), 363-81; Arlinger (2003) 'Negative consequences of uncorrected hearing loss – a review'. *International Journal of Audiology*, 42 (2), 17-20; Monzani et al (2008) 'Psychological profile and social behaviour of working adults with mild or moderate hearing loss'. *Acta Otorhinolaryngologica Italica*,	

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						28 (2), 61-6. [12] Appollonio et al (1996) Effects of sensory aids on the quality of life and mortality of elderly people: A multivariate analysis. *Age and Ageing*, 25, 89-96; Genther et al (2013) Association of hearing loss with hospitalization and burden of disease in older adults. *Journal of the American Medical Association*, 309 (22), 2322; Karpa et al (2010) Associations between hearing impairment and mortality risk in older persons: the Blue Mountains Hearing Study. *Annals of Epidemiology*, 20 (6), 452-9. [13] Saito et al (2010) Hearing handicap predicts the development of depressive symptoms after three years in older community-dwelling Japanese. *Journal of the American Geriatrics Society*, 58 (1), 93-7; Monzani et al (2008) Psychological profile and social behaviour of working adults with mild or moderate hearing loss. Acta Otorhinolaryngologica Italica, 28	

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						(2), 61–66; Eastwood et al (1985) Acquired hearing loss and psychiatric illness: an estimate of prevalence and co-morbidity in a geriatric setting. *British Journal of Psychiatry*, 147, 552–556. [14] Lin FR et al. (2011) 'Hearing loss and incident dementia'. *Archives of Neurology*, 68 (2), 214-220; Gurgel et al (2014) Relationship of Hearing Loss and Dementia: A Prospective, Population-Based Study. *Otology & Neurotology*. 35 (5), 775-781; Albers et al (2015) At the interface of sensory and motor dysfunctions and Alzheimer's disease. *Alzheimers and Dementia Journal*, 11 (1), 70–98. [15] Action on Hearing Loss (2013) Joining up, Available at: www.actiononhearingloss.org.uk/joiningup; Boxtel van MPJ et al (2000) Mild hearing impairment can reduce verbal memory performance in a healthy adult population. *Journal of Clinical and Experimental Neuropsychology*, 22 (1), 147-154; Burkhalter CL et al	

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						(2009) Examining the effectiveness of traditional audiological assessments for nursing home residents with dementia-related behaviours. *Journal of the American Academy of Audiology*, 20 (9): 529-38. [16] Chisholm et al (2007) A systematic review of health-related quality of life and hearing aids: Final report of the American Academy of Audiology task force on the health-related quality of life benefits of amplification in adults. *Journal of American Academy of Audiology*, 18, 151-183; Mulrow et al (1992) Sustained benefits of hearing aids. *Journal of Speech and Hearing Research*, 35 (6), 1402-5; National Council on the Aging (2000) The consequences of untreated hearing loss in older persons. *Head and Neck Nursing*, 18 (1), 12-16; Yueh et al (2001) Randomized trial of amplification strategies. *Archives of Otolaryngology - Head & Neck Surgery*, 127 (10), 1197-204.	

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						[17] Acar et al (2011) Effects of hearing aids on cognitive functions and depressive signs in elderly people. *Archives of Gerontology and Geriatrics*, 52 (3): 250-2; Pronk et al (2011) Prospective effects of hearing status on loneliness and depression in older persons: identification of subgroups. *International Journal of Audiology*, 50 (12), 887-96; Dawes et al (2015) Hearing Loss and Cognition: The Role of Hearing Aids, Social Isolation and Depression. *PLoS ONE,* 10 (3): e0119616; National Council on the Aging (2000) The consequences of untreated hearing loss in older persons. *Head and Neck Nursing*, 18 (1), 12-16. [18] Amieva et al (2015) Self-Reported Hearing Loss, Hearing Aids, and Cognitive Decline in Elderly Adults: A 25-Year Study. *Journal of the American Geriatrics Society*, 63 (10), 2099-2104; Dawes et al (2015) Hearing Loss and Cognition: The Role of Hearing	

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						Aids, Social Isolation and Depression. *PLoS ONE,* 10 (3): e0119616; Deal et al (2015) Hearing impairment and cognitive decline: A pilot study conducted within the atherosclerosis risk in communities neurocognitive study. *American Journal of Epidemiology*, 181(9), 680-90. [19] Davis et al (2007) Acceptability, benefit and costs of early screening for hearing disability: A study of potential screening tests and models. *Health Technology Assessment*, 11, 1–294. [20] Kiani R and Miller H (2010) Sensory impairment and intellectual disability. *Advances in psychiatric treatment*, 16, 228–235. [21] Timehin, C. and Timehin, E (2004) Prevalence of hearing impairment in a community population of adults with learning disability: access to audiology and impact on behaviour. *British Journal of learning disabilities*, *32* (3), 128-132. [22] Ringham (2012) Access All	

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						Areas. Available at: www.actiononhearingloss.org.uk/accessallareas [23] Our Health in Your Hands (2012) Survey of BSL users about access to communication support in healthcare. Available at: https://www.actiononhearingloss.org.uk/get-involved/campaign/equal-treatment/the-problem/survey-of-bsl-users.aspx [24] SignHealth (2014) Sick of it. Available at: http://www.signhealth.org.uk/sickofit/ [25] Fellinger et all (2012) Mental health of deaf people. *The Lancet*, 379 (9820), 1037-1044. [26] Department of Health (2002) A sign of the times. Modernising health services for people who are deaf; Department of Health (2005) Mental health and deafness; towards equity and access; NHS England (2013) NHS standard contract for specialised mental health services for deaf people. C04/S/a. Available at:	

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						https://www.england.nhs.uk/commissioning/wp-content/uploads/sites/12/2013/06/c04-deaf-mh.pdf [27] NICE (2013) Mental wellbeing of older people in care homes. QS50 [28] NHS England (2015) Accessible Information Standard. SCCI1605. Available at https://www.england.nhs.uk/ourwork/patients/accessibleinfo-2/ [29] NHS England (2015) Accessible Information Standard. SCCI1605. Available at https://www.england.nhs.uk/ourwork/patients/accessibleinfo-2/ [30] SignHealth (2014) Sick of it. Available at: http://www.signhealth.org.uk/sickofit/ [31] NHS England (2015) Accessible Information Standard SCCI 1605. Available at https://www.england.nhs.uk/ourwork/patients/accessibleinfo-2/ [32] NHS England (2015) Accessible Information Standard SCCI 1605. Available at	

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						https://www.england.nhs.uk/ourwork/patients/accessibleinfo-2/ [33] Saito et al (2010) Hearing handicap predicts the development of depressive symptoms after three years in older community-dwelling Japanese. *Journal of American Geriatrics Society*, 58 (1), 93-7; National Council on the Aging (2000) The consequences of untreated hearing loss in older persons. *Head and Neck Nursing*, 18 (1), 12-16. [34] Acar et al (2011) Effects of hearing aids on cognitive functions and depressive signs in elderly people. *Archives of Gerontology and Geriatrics*, 52 (3): 250-2; Mulrow et al (1992) Sustained benefits of hearing aids. *Journal of Speech and Hearing Research*, 35 (6), 1402-5. [35] Davis et al (2007) Acceptability, benefit and costs of early screening for hearing disability: A study of potential screening tests and models. *Health Technology Assessment*, 11, 1–294.	

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						[36] Kiani R and Miller H (2010) Sensory impairment and intellectual disability Advances in psychiatric treatment. 16, 228–235 [37] Action on Hearing Loss (2013) Joining up, Available at: www.actiononhearingloss.org.uk/joiningup [38] Kiani R and Miller H (2010) Sensory impairment and intellectual disability Advances in psychiatric treatment. 16, 228–235; Foundation for people with learning disabilities, 2015. Hearing Loss. Available from: http://www.learningdisabilities.org.uk/help-information/learning-disability-a-z/h/hearing-loss/ [39] NHS England (2015) Accessible Information Standard. SCCI 1605. Available at https://www.england.nhs.uk/ourwork/patients/accessibleinfo-2/ [40] Foundation for people with learning disabilities, 2015. Hearing Loss. Available from: http://www.learningdisabilities.org.uk/help-information/learning-	

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						disability-a-z/h/hearing-loss/ [41] Albers et al (2015) At the interface of sensory and motor dysfunctions and Alzheimer's disease. *Alzheimers and Dementia Journal*, 11 (1), 70–98; Gurgel et al (2014) Relationship of Hearing Loss and Dementia: A Prospective, Population-Based Study. *Otology & Neurotology*. 35 (5), 775-781; [42] Lin FR et al. (2011) 'Hearing loss and incident dementia'. Archives of Neurology, 68 (2), 214-220; Lin et al (2013) Hearing loss and cognitive decline in older adults. *Internal medicine*, 173 (4), 293-299 [43] Dawes et al (2015) Hearing Loss and Cognition: The Role of Hearing Aids, Social Isolation and Depression. *PLoS ONE,* 10 (3): e0119616 Deal et al (2015) Hearing impairment and cognitive decline: A pilot study conducted within the atherosclerosis risk in communities neurocognitive study. *American Journal of Epidemiology*, 181(9), 680-90; Amieva et al (2015) Self-	

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						Reported Hearing Loss, Hearing Aids, and Cognitive Decline in Elderly Adults: A 25-Year Study. *Journal of the American Geriatrics Society*, 63 (10), 2099-2104. [44] Action on Hearing Loss (2013) Joining up, Available at: www.actiononhearingloss.org.uk/joiningup; Boxtel van MPJ et al (2000) 'Mild hearing impairment can reduce verbal memory performance in a healthy adult population'. Journal of Clinical and Experimental Neuropsychology, 22 (1), 147-154; Burkhalter CL et al (2009) Examining the effectiveness of traditional audiological assessments for nursing home residents with dementia-related behaviours. *Journal of the American Academy of Audiology* 20 (9): 529-38. [45] Kiani R and Miller H (2010) Sensory impairment and intellectual disability *Advances in psychiatric treatment*. 16, 228–235; Foundation for people with learning disabilities, 2015. Hearing Loss.	

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						Available from: http://www.learningdisabilities.org.uk/help-information/learning-disability-a-z/h/hearing-loss/	
284	SH	British Association of Music Therapy (BAMT)	Short	General	General	There is particular concern that the recommendations contained in this guidance may exclude those people who have a moderate, severe or profound learning disability owing to the fact that all of the guidance cited in this document will rely heavily, although not exclusively, on the use of the spoken word. Music therapists are able to offer detailed assessment and treatment of a person with a learning disability (of all degrees), and mental health needs without having to rely on verbal communication. Detailed observation of the person's use of the creative medium and the relationship that they build with the therapist provides important information for both the care team around them as well as the	Thank you for your comment. People with more severe learning disabilities are included within our scope, and all recommendations, aside from those that specifically state otherwise, relate to all people with learning disabilities. Throughout the guideline development process the GC were mindful of the needs of those with more severe learning disabilities. The GC were aware that the strengths and needs of this population are incredibly diverse, and accordingly were reluctant to specify that interventions should be only be made available to a particular sub-group (for example milder or more severe learning disabilities) without a specific reason relating to the available evidence (see recommendation 1.9.5). CBT is one of the few interventions that is specifically listed as there was sufficient evidence for the GC to make an evidence-based recommendation. We do not believe that all listed interventions require verbal communication (see recommendations 1.9.6-1.9.9). The principles for psychological interventions

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						individual themselves which over time may lead to an improvement in mental health when delivered as part of an individualised care package. Music therapists are one of the few professions that work with the individuals in the first instance as opposed to the care team around them, although this aspect of work is developed as therapy progresses. The predominant use of Cognitive Behavioural Therapy, as suggested in these guidelines, will be challenging in practice owing to its high reliance on higher cognitive abilities and the need for the person to express themselves verbally. The British Association for Music Therapy is concerned that these guidelines and recommendations imply that therapy is only available to those people who have access to verbal communication.	(see recommendations 1.9.2-1.9.4) also allow for a wide range of strengths and difficulties, and appropriate adaptations to accommodate these. Unfortunately no evidence was received from the BAMT during the call for evidence from stakeholders. We are not now able to accept further submissions.

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						The British Association for Music Therapy members have many years of experience of providing individual and group music therapy to people on the learning disability spectrum and/or mental health needs, and would be very willing to submit its experiences to the NICE sharing learning database.	
285	SH	British Association of Music Therapy (BAMT)	Short	General	General	Music therapy is recognised as a cost-effective non-pharmacological intervention for people with learning disabilities and/or mental health issues. The recommendations do not refer to the role Allied Health Professionals, such as music therapists, play in supporting the well-being and mental health of people with Learning Disabilities. There needs to be greater signposting to music therapy services and other Allied Health Professions to ensure that service users are aware of the full range of	Thank you for your comment. No evidence meeting our inclusion criteria was found for music therapy as an intervention. Therefore the GC were unable to recommend music therapy as a specific intervention. Our approach is to stress competencies rather than specific professional groups, as local service configurations will vary (see recommendations 1.2.9-1.2.11 on staff training and 1.3.1 on communication). Specific professional groups are listed only where the GC agree that it is absolutely essential to do so (see recommendations 1.7.5 and 1.10.8). Examples of allied health professionals are given at various points within the guideline (for example see 'staff' within the glossary).

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						interventions available to them. This would be a cost-free implementation exercise but would require pro-active sharing and cascading of information about music therapy services by commissioners, service leaders and managers and music therapists. Information about services would be need to be made available in a range of appropriate formats for service users, carers, families and practitioners. This could be done in partnership with the professional body for music therapy, the British Association for Music Therapy.	Signposting to services is a local implementation consideration, and beyond the remit of this guideline.
286	SH	British Association of Music Therapy (BAMT)	Short	24	11	It is disappointing to see that the recommendations in the section that are concerned with Social and Physical Environment Interventions do not include therapeutic interventions such as music therapy which may help as a preventative and supportive measure with those people who are	Thank you for your comment. No evidence was found for the use of music therapy for people with learning disabilities and mental health problems. In the absence of evidence no recommendations could be made in this area.

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						in education, foster placements and adoptive placements, resulting in a probable reduction in placement breakdown. Health intervention of a therapeutic nature may also be necessary to prepare and support someone to be able to engage in their education or other activities that are helpful and meaningful to them. Therapy developed skills such as relationship skills, self – confidence and self- worth are necessary prerequisites for engagement in such activity. As in the first comment the British Association for Music Therapy ask that the needs of all people with a learning disability, regardless of their level of verbal and/or cognitive skill are considered and provided for in this guidance.	
287	SH	British Association of Music Therapy (BAMT)	Short	26	6	The occupational aspirations as included in the guidance will require an extensive range of health and social interventions as preparatory and supportive measures available to a group of people who have a wide variety of health and social	Thank you for your comment. No evidence was found investigating music therapy as an occupational intervention. Therefore the GC are unable to provide such a recommendation.

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						needs. It is considered that the identification of possible challenges when in paid employment in particular for someone with a learning disability and additional mental health needs should include those of a more emotional and intra and inter-personal nature for which therapy may be one way of giving much needed support. Music therapy is recognised as a cost effective non-pharmacological intervention which is a supportive measure for people considered in these recommendations.	
288	SH	Royal College of Nursing	General	General	General	The Royal College of Nursing welcome steps to develop these guidelines.	Thank you for your comments.
289	SH	Royal College of Nursing	General	general	general	The RCN invited views from members who work with people with learning disability. The comments below reflect the views of members of the RCN Northern Ireland Learning Disability Nursing Network, along with comments on behalf of the RCN NI Professional Development Department.	Thank you for your comments.

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290	SH	Royal College of Nursing	Full	general	general	It is concerning that there is a clear lack of nursing input to the committee in developing this guideline, and a lack of acknowledgment of the role of the Registered Learning Disability Nurse in the delivery of services.	Thank you for your comment. One of our GC members is a registered mental health and learning disabilities nurse. Additionally within section 2.6 of the full guideline paragraphs 3 and 4 discuss the composition of learning disabilities teams and explicitly mention the role of nurses.
291	SH	Royal College of Nursing	Full	general	general	Overall the key elements of assessment, diagnosis and treatment have been addressed. The emphasis given to psychological therapies as first line treatment is pleasing. However, greater emphasis is required regarding the importance of the use of the principles of positive behaviour support in both the assessment and treatment sections.	Thank you for your comment, the GC acknowledge that PBS is increasingly used as an overarching framework to describe a range of appropriate strategies to support people with a learning disability and behaviour that challenges. The GC considered the evidence for PBS as an overall framework and were unable to identify any evidence of sufficient quality to support a recommendation for the adoption of PBS.
292	SH	Royal College of Nursing	Full	general	general	Mental ill health problems in the learning disability populations are commonly overlooked by staff. There is a reluctance of staff in mental health services to provide their services to people with a learning disability. There is little mention of this within the document	Thank you for your comments. The Guideline Committee shared you concerns that diagnostic overshadowing is highly prevalent, and that service users may 'fall between the gaps' of services that do not feel appropriately trained to deliver a high quality service to people with learning disabilities. The recommendations within sections 1.2.5-1.2.6 (access to services), 1.2.10 (staff training), 1.3.1

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						and until this discrepancy is overtly highlighted and tackled, many services will continue to exclude people with a learning disability. This is a key challenge. Learning disability services therefore try to develop their own service provision, which, although laudable, means that people with learning disabilities do not have access to the skills and competencies available within mainstream mental health services. Integration of adult mental health services and Child Adolescent Mental Health Services (CAMHS) services with local learning disability services is essential. There is an excellent example of service development in this area in an intellectual disability service which is fully integrated within a CAMHS structure in the Southern Health and Social Care Trust in Northern Ireland.	(communication needs) 1.7 (identification) and 1.2.9, 1.8.4 and 1.8.6 (diagnostic overshadowing) attempt to address these important issues.
293	SH	Royal	Full	general	general	The implementation of the	Thank you for your comments. The Guideline

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		College of Nursing				guidelines will require capable and competent staff. There will be presumably significant cost implications in terms of ensuring that staff have the necessary knowledge, skills and experience in safely, effectively and compassionately meeting mental health needs for the learning disability population, both in health and social care services, and special needs education services. The cost associated with designing, commissioning, delivering, implementing and evaluating this training is justified.	Committee agree that any costs are justified in this instance and expect services to take responsibility for training their staff so that they will feel able to provide safe and effective care. This is in line with national policy following Winterbourne view.
294	SH	Royal College of Nursing	Full	general	general	There is no reference to the mental health needs of the hospital inpatient learning disability population. As hospitals for people with a learning disability retract and restructure, the emphasis on inpatient care is around admission of those with serious mental illness which is complicated by a learning disability. Retraction of inpatient hospital provision means a	Thank you for your comments. As you indicate within your response, following Winterbourne view there is an appreciation that long-term inpatient care is often not in the best interests of people with learning disabilities, who are now being moved from long-term inpatient care into the community. Therefore to provide recommendations for this setting would contradict current policy. The needs of those with challenging behaviour and a learning disability, and individuals with a learning

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						decrease in numbers of staff required to work onsite, with a greater emphasis on community based treatment. There is a challenge to ensure that staff in both settings are capable, competent and possess the necessary knowledge, skills and experience to safely, effectively and compassionately meet the needs of those in their care. "Transition" of staff from one type of service provision to another (hospital based to community based, and upskilling of staff to meet the evolving and intensifying needs of the patient population) must be adequately managed to ensure that they are appropriately trained to embrace their new roles and positions. The cost associated with designing, commissioning, delivering, implementing and evaluating this training is justified.	disability only who are long-term inpatients are beyond the scope of this guideline. The needs of those with serious mental illness have been addressed (see recommendation 1.2.6 for explicit reference). The Guideline Committee agree that staff training will need to be adapted to fit this shift in care provision, and expect that care providers will respond appropriately to this need. We agree that these costs are justified.
295	SH	Royal College of Nursing	Full	general	general	The mental health needs of children with a learning disability should come towards the start of	Thank you for your comment. We agree that prevention, rather than reactive strategies, should be prioritised and have reordered the document

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						the document – early intervention being key.	accordingly. However as many sections apply to both children and adults to separate out the needs of children would be duplicative and in some cases discriminatory, as decisions over intervention should be made based upon the needs of the individual rather than simply age.
296	SH	Royal College of Nursing	Full	general	general	The introduction and increased use of electronic care records is presenting challenges regarding ensuring information, such as care plans, is presented in a format suitable for individual people with learning disability.	Thank you for your comment. This issue of electronic care records is outside of the scope of this guideline.
297	SH	Royal College of Nursing	Full	general	general	If these guidelines are adopted by the Department of Health, Social Services and Public Safety (DHSSPS) Northern Ireland, there will be some challenges around assessment of capacity and consent for care and treatment, as legislation to support practice around assessing capacity does not currently exist in NI. Other challenges in this area lie ahead for NI as we await the implementation of local primary legislation and supporting subordinate legalisation and codes of practice.	Thank you for your comments. NICE guidelines are written for the use of practitioners in England, although we appreciate that those in other parts of the UK may also choose to adopt them as best practice. Local implementation is beyond our remit.

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298	SH	Royal College of Nursing	Full	general	general	It is acknowledged that these guidelines are relevant in the first instance to England and Wales and may not be adopted by NI. Where responses in this document references Northern Ireland, they are based on NI context. The current health and social care system in Northern Ireland may differ in part for England. Although colleagues in NI have commented on these draft guidelines, it is acknowledged that specific endorsement and implementation of the guidelines in NI will be determined by the DHSSPS.	Thank you for your comments.
299	SH	Royal College of Nursing	General	General	General	**Do any recommendations represent a substantial increase in costs, and do you consider that the reasons given in the guideline are sufficient to justify this?** Provision of psychological interventions may incur additional costs to trusts. Whilst psychological interventions are currently available	Thank you for your comment. We agree that although there may be some costs involved in ensuring that the workforce is appropriately skilled that these costs are justified as they are good practice, likely to lead to better outcomes for service users and are an important equality consideration. The Guideline Committee assert that these fairly minimal initial costs are likely to lead to lower costs in the longer term due to the more effective treatment provided and associated reduction in overall burden on services.

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						the guidelines recommend a range of interventions which may not currently be available within trusts. Additional costs may be incurred to train staff in new psychological interventions. Recommendations to 'Provide Social and Physical environment interventions and adaptations and occupational interventions' will result in increased cost to trusts / services. Whilst all of the recommendations noted are recognised as good practice and positive interventions for service users there will be significant cost will be incurred to deliver these interventions.	We believe that the adaptations recommended for the social and physical environment, taken within the context of the significant short and long-term costs associated with failing to consider these factors, are in fact likely to accrue cost-savings. Additionally, for those with more severe learning disabilities, these types of adaptations may be the most effective available and therefore these represent an equality issue. Regarding occupational interventions, there is evidence from similar populations such as those with an ASD and learning disabilities that occupational support can be helpful. Associated costs are again justified as they help to remove barriers to full participation in society and are likely to result in cost savings from lower frequency of service use in the long run.
300	SH	Royal College of Nursing	Full	General	General	**Areas that will have the biggest impact on practice; which will be challenging to implement - for whom and why**: Recommendation 1.3.2 will be challenging to implement due to lack of capacity legislation in Northern Ireland. UK codes of	Thank you for your comments. NICE guidelines are written for the use of practitioners in England, although we appreciate that those in other parts of the UK may also choose to adopt them as best practice. Local implementation is beyond our remit. Recommendations 1.2.9 and 1.2.10 address the need for all staff to have the skills necessary to

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						practice and guidance will be available and useful to help guide and inform practitioners. Recommendation 1.6: Conducting a Mental Health (MH) assessment - This continues to be a challenge as mental health staff report that they do not feel competent in assessing individuals with a learning disability. Mental Health professionals have been reluctant to accept referrals for individuals with a learning disability (LD) advising that such assessments should be carried out by the LD team / professionals. LD professionals are not trained or skilled in MH assessment however are willing to assist in whatever way possible. Recommendation 1.6.12: Currently, unaware of any Assessment tools developed / adapted to assess the MH of those with a learning disability. Recommendation 1.6.23 Mental	competently work with people with a learning disability, and to know where to refer onwards if they feel that they require more specialist input. Please see Chapter 4 of the full guideline for the review of assessment tools for use in people with learning disabilities. The tools that were found to be of sufficient quality are listed within recommendations 1.8.14 to 1.8.16. The Guideline Committee agree that mental health care plans should always be developed for the individual and specifically address their needs. We believe this is catered for by the requirement for individuals to have a key worker who manages the care plan.

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						Health care Plan will need to be developed for use.	
301	SH	Royal College of Nursing	Full	21	2.1.1	2.1.1 Is it not the case that 'many' definitions of learning disability require a person's cognitive ability to be below the 2nd standard deviation below the mean (typically indicated by an IQ below 70)– as opposed to 'some'?	Thank you for your comment. We have now amended the wording of this sentence to state that 'many' rather than 'some' definitions require the person to have an IQ of less than 70.
302	SH	Royal College of Nursing	Full	General	General	The introductory section appears, at times, to be overly filled with technical jargon (e.g.: 2.5.2: 'neural circuits supporting attention, memory, and emotional regulation overlap heavily with the pathways on which allostatic load has an influence' which, as a psychologist, used language untypical of clinical decision making/reporting).	Thanks you for your comment. The introduction is designed to provide a brief authoritative overview of the topic, including biological mechanisms. Therefore it is necessary to apply technical terminology. We have carefully reviewed this section to ensure readability.
303	SH	Royal College of Nursing	Short	15	1.6.9	There are several references made to sharing information with families and carers (e.g. 1.6.9). Should a greater emphasis be placed on the individual's choice in this matter, when they have capacity to make this choice?	Thank you for your comment. This is an incredibly important issue that the GC discussed this at length. We agree that the individual should be the one to make the choice over who is involved, other than in exceptional circumstances. The GC have tried to balance this with mentions of information sharing to encourage this where appropriate (see

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							recommendation 1.3.4).
304	SH	Royal College of Nursing	Short	12	18	In the short version it specifies that the person carrying out the assessment should be someone experienced in learning disability and mental health. Later in the guidelines it introduces that they should also do a physical health screen. Should that not be referral to a general practitioner or practice nurse for a general physical health screen? The recommendation does not specify a prerequisite for skills in physical health screening and indeed it maybe a social worker carrying out the assessment. This needs to be clearer.	Thank you for your comment. We believe that you are referring to the annual health check when you mention 'physical health screen'. The annual health check is not a specific mental health assessment, but rather a check conducted by GPs that should already occur for people with learning disabilities.
305	SH	Royal College of Nursing	Full	General	General	Should the guideline committee consider discussing Pharmaceutical Benefits Scheme (PBS) approaches, and relevant evidence when discussing psychological interventions (perhaps especially with people for whose learning disability has a greater impact)?	Thank-you for your comment. This is outside of our scope.
306	SH	Royal	Full	253	8.1	8.1 Organisation and Service	Thank you for your comment, it is not NICE policy to

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		College of Nursing				delivery – Should reference be made to the Learning Disability Professional Senate document: Delivering Specialist Community Learning Disabilities Health Team Support to People with Learning Disabilities and their Families or Carers?	include reference to specific policy documents in the recommendations.
307	SH	Royal College of Nursing	Easy Read	General	general	The 'Easy Read' version – Is there evidence that using drawings like this aids individuals' understanding?	Thank you for your comment. We did not specifically review the evidence for 'Easy Read'. However, our service user focus group requested an Easy Read version, and this is consistent with what was done for NICE's guideline on challenging behaviour and learning disabilities
308	SH	South Staffordshire and Shropshire NHS Foundation Trust	Full	General	General	Feedback received within the Trust was very positive, the draft guideline has been well received.	Thank you for your comments
309	SH	South	Full	General	General	In relation to the title, feedback has	The Guideline Committee appreciate this comment.

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		Staffordshire and Shropshire NHS Foundation Trust				indicated a preference for "Mental ill Health" or "Mental Health need" instead of "Mental Health problems". The word 'problem' was perceived a more negative descriptor.	However this is the approved NICE wording, which is used consistently across all NICE guidelines. Therefore we are unable to make this amendment.
310	SH	South Staffordshire and Shropshire NHS Foundation Trust	Full	General	General	In relation to the title, feedback has indicated that the inclusion of recovery / recovery focused / enablement rather than just management consider management of recovery for example.	Thank you for your comments. The title of the guideline was approved by NICE and our stakeholders, and therefore we are unable to make this amendment.
311	SH	South Staffordshire and Shropshire NHS Foundation Trust	Full	196	28	Bullet point six – Confusing statement, line 5 indicates reviews every 3-4 weeks then line 6 indicates reviews every 6 weeks.	Thank you for your comment. These bullet points describe the statements that were endorsed by the GC using the nominal group technique. Both statements were endorsed, however upon further discussion the GC decided not to impose a time limit. The wording within the statements 'The GC endorsed statements stating that' and LETR table 'Although the GC initially endorsed statements calling for specific timescales for review of medications (see clinical evidence statements), they decided upon discussion that this should be dependent upon the individual and their circumstances. Therefore they did not make a specific recommendation on this.' has been amended so that this is clearer.

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312	SH	South Staffordshire and Shropshire NHS Foundation Trust	Full	198	12	Recommendation 43 bullet point 1 – should this include the phrase if appropriate rather than "consult with specialists prescribing medication for any other conditions" which is all encompassing in every situation.	Thank you for your comment. This recommendation has now been reworded to include 'where necessary'. The new recommendation number is 1.10.4.
313	SH	South Staffordshire and Shropshire NHS Foundation Trust	Short	7	21	'services should train all staff who may come into contact with people with learning disabilities' - does this require more specific wording? Regarding statutory services responsibilities to train staff, we assume this refers to staff within the organisation not a more general expectation to train staff in other organisations we work with?	Thank you for your comment. Decisions about training providers are a local implementation issue and beyond our remit.
314	SH	South Staffordshire and Shropshire NHS Foundation Trust	Short	11	24 25	Should this state 'If a person with learning disabilities shows any changes in behaviour without a clear function or reason'.	Thank you for your comment. The GC were concerned that changes in behaviour are often mistakenly attributed to recent events and that early warning signs of mental ill health are often missed as a result. It is for this reason that the current wording was chosen.
315	SH	South Staffordshire and	Short	11	27	Should this state 'consider a mental health problem while ruling out any physical health conditions or pain'	Thank you for your comment. As this is relating to case identification, we do not expect that the individual working with the person with a learning

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		Shropshire NHS Foundation Trust					disability (for example a support worker) will always be qualified to make this judgement. The inter-relationship between physical and mental health is addressed within recommendation 1.8.4 as part of an assessment with a competent member (or members) of staff.
316	SH	South Staffordshire and Shropshire NHS Foundation Trust	Short	16	8	Should we also bullet point the most reliable or valid tool before cost?	Thank you for your comment. We agree that reliability and validity are paramount, however we believe that this is implied by the request to use specially developed or adapted tools within bullet point 1 of this recommendation (revised number 1.8.12).
317	SH	South Staffordshire and Shropshire NHS Foundation Trust	Short	13	21	Should there be more detail here in terms of the potential differences in presentation, also should we reference first that people with learning disabilities can present in the same way as the general population (particularly people with mild learning disabilities)	Thank you for your comment. As there are a wide range of ways that mental health problems may present in this group it would be misleading to provide examples here. An appropriately trained clinician should be aware of this possibility. The GC agreed that the way that the recommendation is phrased currently emphasises that different presentations are more likely in those with severe learning disabilities.
318	SH	South Staffordshire and Shropshire NHS Foundation	Short	23	22	Under prescribers should record, should reference be made in the short guidance to consent, capacity and best interests at this point.	Thank you for your comment. This is already covered by the earlier section on capacity and consent recommendations 1.3.2-1.3.3.

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319	SH	South Staffordshire and Shropshire NHS Foundation Trust	Short	24	9 10	Short we reference 'minimise the risk of placement breakdown by taking particular care to fit these to the needs of the person', for adults as we already reference this for young people and children in 1.10.2 (page 24 line 28)	Thank you for your comment. This point is covered for adults within the final bullet point of recommendation 1.5.2.
320	SH	South Staffordshire and Shropshire NHS Foundation Trust	Short	28	21	This sentence reads as if autism is a Mental health condition when read in conjunction with the preceding sentence/paragraph, the same applies to behaviour that challenges in the same sentence.	Thank you for this comment. We agree that this could be confusing for the reader and have adjusted the wording accordingly. It now reads 'Psychosis, bipolar disorder, dementia, behaviour that challenges and neurodevelopmental conditions such as autism and attention deficit hyperactivity disorder are all more common…'
321	SH	South Staffordshire and Shropshire NHS Foundation Trust	Short	23	8	Should this bullet point state 'consider referral to community learning disability teams if support is needed for physical investigations (for example blood tests)', rather than 'consider providing support'. Should this point be preceded by a statement regarding reasonable adjustments regarding physical investigations and joint working between learning disability and mental health teams?	Thank you for your comment. We have now altered the wording of the recommendation to more clearly delineate responsibilities. The 5th bullet point of revised recommendation 1.10.4 now reads 'assess whether support from community band learning disabilities nurses is needed for physical investigations (such as blood tests)'. Reasonable adjustments and organisation of care are set out within recommendation 1.2.2, and therefore we decided that there was no need to repeat that here.

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						Should this point be followed by a statement related to least restrictive options when supporting any physical tests?	Use of the least restrictive option is laid out in statute and therefore we do not believe that it is necessary to list this here.
322	SH	Nottinghamshire Healthcare NHS foundation trust	Full	22	41	We are concerned that pharmacists are not listed among the healthcare professionals listed in this section. There are community pharmacists who dispense prescriptions written in primary care. There are specialist clinical pharmacists who work in secondary care and advise on medication use and dispense prescriptions written by consultant psychiatrists for ID inpatients and outpatients being treated for mental health disorders.	Thank you for your comment. We have now explicitly listed pharmacists within sections 2.1.4 of the full guideline.
323	SH	Nottinghamshire Healthcare NHS foundation trust	Full	23	1	"More children and young people are identified as having learning disabilities" Could it be that once out of educational environment those people with LD are not counted and therefore apparently disappear? Many people described as having a learning disability receive care in a general hospital environment with no specialist support or understanding of their	Thank you for your comment. We agree that the wording here was confusing and have now removed the following sentence 'then, as young people and adults gradually learn skills, they may no longer need support to lead independent lives' so that it is clearer.

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						difficulties	
324	SH	Nottinghamshire Healthcare NHS foundation trust	Full	31	28	We are concerned that there is no mention of pharmacist as team members. This document mentions poly-pharmacy 8 times and does not mention pharmacy or pharmacist at any point. Poly pharmacy has been flagged as a particular problem see p 103 section 4.6 points 6, 11 and 13. On p and 6.1 p 177 line 10 where medication reviews, interactions between medications, adverse effects, providing information to persons and families, these are all areas where a pharmacist skill could be utilized. Although many people with LD live in the community and many inpatient beds in specialist units have been closed pharmacists with specialist expertise in medicines use in people with LD are still available to be consulted and could provide information to patients and carers. Community pharmacists are available in primary care and could develop expertise in this area and	Thank you for your comment. Local service configurations vary and therefore we often focus on competence rather than naming specific staff groups. We have however now listed pharmacists within both the short and full guideline.

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						specialist secondary care pharmacists could engage in cross sector working to bridge this gap.	
325		Nottinghamshire Healthcare NHS foundation trust	Full	196	23	Concerning the sentence containing the phrase "support for people who live alone to take their medication", we feel this instruction would benefit from some additional clarification of what might be meant by support. Support could be a compliance aid or it could be a carer calling at the person's home or a telephone support service. The expense of these provisions vary greatly but the cost may be off set against cost of hospital admission or decrease care costs resulting from poor health. Provision of compliance aids may have to be funded by the persons themselves if funding is not available in primary care.	Thank you for your comment. We agree that appropriate support will vary depending upon the service user and their needs. We believe that it is an issue of clinical judgement to decide this. Funding is beyond our remit, and is an issue for national and local government.
326	SH	Nottinghamshire Healthcare NHS foundation trust	Full	177	25	We wonder if this sentence containing "current I consensus" is correct, could the " I " be a typo?	Thank you for pointing this out, it has been amended.

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327		Nottinghamshire Healthcare NHS foundation trust	Full	196	9	We feel that the possibility of the development of side effects during ongoing pharmacotherapy should also be considered in addition to that at the start or discontinuation for therapy. The impact of increasing age should be considered as a risk factor since decreased renal failure, and liver function, increased sensitivity of receptors and decreased cognitive function could have a detrimental effect on the person ability to tolerate medication.	Thank you for your comment. The GC discussed and agreed with these points, however this was deemed to be a level of detail inappropriate for a guideline. These issues are mentioned within relevant prescribing guidelines (such as the Frith guidelines, referenced within the introduction).
328		Nottinghamshire Healthcare NHS foundation trust	full	196	33	We consider that it would be helpful to document a list of current medication, including the dose and frequencies of purpose of each medication, each time a review takes place. This would facilitate medication review and the production of drug histories over long periods of time. We find patient notes frequently lack detailed descriptions of a persons' presentation, for example the medication was stopped because the person was experiencing	Thank you for your comment. We address this issue within the recommendation section on annual health checks (1.6.3) however we view the recording of sufficient information within the patient notes to be an issue of good clinical practice and an issue for local services to address.

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						adverse effects, but neither the actual nature of the side effects nor their impact is explicitly stated. If such details are given it facilitates decision making and the choice of medication in the future.	
329	SH	Nottinghamshire Healthcare NHS foundation trust	Full	196	44	We would like the guideline authors to consider including pharmacists in this recommendation. Specialist pharmacists in learning disabilities in secondary care are also highly skilled and so able to discuss pharmacotherapy and drug interactions.	Thank you for your comment. We have now added explicit mention of pharmacists within the professionals section of the 'Terms used' section of the short guideline.
330	SH	Nottinghamshire Healthcare NHS foundation trust	Full	198	15	We feel that a pharmacist could be also be included in a discussion between consultant specialist to avoid possible interactions and poly-pharmacy, since they are skilled in all areas of medicines management	Thank you for your comment. Pharmacists are listed as one of the professional groups involved in patient care.
331	SH	Nottinghamshire Healthcare NHS foundation trust	Full	198	25	We have frequently heard comments from outpatients, treated with psychotic medication from their GP, that they do not receive regular monitoring. Please could a reference be made to the frequency that this monitoring should take	Thank you for your comment. The need for regular review is covered by recommendations 1.10.5 and 1.10.7. The GC did discuss the frequency of reviews, but agreed that as this is dependent upon the condition, side-effects etc. that a one-size-fits-all approach would not be helpful. This is discussed further within the relevant LETR section (6.3) of the

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						place and that the frequency of that monitoring be agreed between specialist prescribers and individualized to each individual's risks.	full guideline.
332	SH	Nottinghamshire Healthcare NHS foundation trust	Full	198	40	Some medications used to treat mental health conditions have particular toxicities e.g. lithium and clozapine. We are concerned that this recommendation does not include a recommendation to include instructions on serious toxicity and the actions to be taken if these serious toxicities arise.	Thank you for your comment. Both lithium and clozapine have strict protocols in place for their monitoring for the reason you describe. The GC agreed that the potential for toxicity from the drugs you mention and the monitoring of this is not a special consideration for this group. In combination with recommendation 1.10.6 related to the reporting of side effects, the GC were in agreement that this was sufficient detail for the guideline.
333	SH	Nottinghamshire Healthcare NHS foundation trust	General	7	20	We would like to know who will do this training and how will it be funded. Is any training currently available and will any pharmacy expertise be sought to advise or provide this training?	Thank you for your comment. It is expected that services will provide the training needed for their staff to provide safe and effective care. The choice over how best to do this is a local implementation issue and beyond our remit.
334	SH	Nottinghamshire Healthcare NHS foundation trust	general	9	22	Which type of health-care professional will discuss the treatment options with the person and provide information?	Thank you for your comment. We would expect that a range of professionals could be trained and competent to take on this role within services.

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335	SH	Nottinghamshire Healthcare NHS foundation trust	general	16	20	Is the Glasgow depression scale assessment tools currently used to assess depression, what scale can be used if the person has very limited communication skills?	Thank you for your comment. The evidence for assessment tools appropriate for use in people with learning disabilities was reviewed, however few tools that met our inclusion criteria were found. Those that were found have been listed within the recommendations. The GC noted that the Glasgow Depression Scale does have a carer completed version, which can be used with this population and is mentioned within the recommendation. The GC were aware that the lack of useful tools, particularly for those individuals with limited communication skills, is a real problem. It is for this reason that a research recommendation has been made in this area.
336	SH	Nottinghamshire Healthcare NHS foundation trust	general	18 19	General	Do GPs do these general health checks, has this been audited and what should be done where the patient is unwilling or unable to engage in this monitoring. Will GPs be funded to provide longer appointments to enable these lest to carried out in a way acceptable to the person with LD	Thank you for your comment. This is an existing service, currently provided by around 80% of GPs, with around 50% uptake. The physical aspect of the health check was stressed within the Challenging Behaviour Learning Disabilities guideline. Funding arrangements are beyond our remit.
337	SH	Nottinghamshire Healthcare NHS foundation	general	General	General	How many GPs are there with special interest in LD to carry out this specialist service	Thank you for your query. NICE do not hold data on staff numbers.

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		trust					
338	SH	Nottinghamshire Healthcare NHS foundation trust	general	19	18	"A review of medication, interactions adverse effects" who currently does this and how many primary or secondary care pharmacist are there who could help with this task?	Thank you for your comment. This will vary according to local service configurations. We do not hold these data and so are unable to answer your query.
339	SH	Nottinghamshire Healthcare NHS foundation trust	general	General	General	How many GPs are there with special interest in LD and how do they liaise with psychiatrist in secondary and tertiary care services?	Thank you for your query. NICE do not hold data on staff numbers. Care pathways will vary at a local level.
340	SH	Nottinghamshire Healthcare NHS foundation trust	general	25	7	Are there any Early Intervention Teams that work with people with LD with MH problems	Thank you for your comment. We do not hold these data on service providers.
341	SH	Nottinghamshire Healthcare NHS foundation trust	general	28	8	Why are pharmacist not included in the list of Allied health professionals	Thank you for your comment. The list is not intended to be exhaustive, however pharmacists have now been added to the list of professionals
342	SH	Nottinghamshire Healthcare	general	33	General	"Randomized control trials to compare service provision" Is this the right term or should this be	Thank you for your comment. Following further discussion, the GC have decided to replace this research recommendation with another investigating

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		NHS foundation trust				studies or cohort studies. What is going to be done to find these studies or trials?	service configuration and experience (The experiences of people with learning disabilities and mental health problems in services).
343	SH	Nottinghamshire Healthcare NHS foundation trust	general	General	General	No mental health service pharmacists or mental health nurses were included in this committee why was this	Thank you for your comment. One of the committee members is a registered mental health and learning disabilities nurse. During the stakeholder workshop (conducted during the scoping phase) all registered stakeholders were invited to comment on the proposed GC constituency.
344	SH	Nottinghamshire Healthcare NHS foundation trust	General	General	General	The data that backs this guidance is incredible slender. This probable reflect the lack of recognition of this important are of healthcare. We very much hope that this guidance will encourage services to recognize this lack and address this issue.	Thank you for your comments. There is a lack of data available in this area, therefore the GC made recommendations for future research which they hope will help to rectify this.
345		Islington Learning Disability Partnership, Camden & Islington NHS Foundation trust	Full	General	General	The context of the guideline is very well described, detailed manner.	Thank you for your comments
346	SH	Islington Learning	Full	78	4.4	Query regarding why only mentioning Dementia or Psychosis	Thank you for your comment. The wording here reflects the acknowledgement by the GC that local

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		Disability Partnership, Camden & Islington NHS Foundation trust				as a referral reason to psychiatry? Should this not be more detailed?	service configurations, and available professionals, will vary. However the GC wished to stress that in these two circumstances that the referral should be made to a specialist psychiatrist.
347		Islington Learning Disability Partnership, Camden & Islington NHS Foundation trust	Full	103	4.6	We would state you should complete a risk assessment **at all times** instead of considering if this is required.	Thank you for your comment. The GC believed that a risk assessment would not always be needed, and that it would be more appropriate to advise that clinical judgement is used to decide whether or not to conduct a formal assessment of risk. The GC agreed that the mental health assessment, which is updated as new information emerges, contains triggers for a risk assessment (for example social circumstances and drug use). They were concerned that a stipulation to complete a risk assessment at all times would devalue the process, as it can simply become a tick-box exercise. We also received feedback that it can result in a total aversion to risk which can be detrimental to service user quality of life. Therefore we will not be making this amendment.
348		Islington Learning Disability Partnership, Camden &	Full	105	23	Baseline cognitive assessment for patients with Down syndrome, Please see age guidance in BPS and RCpsych dementia guideline and we would recommend adding	Thank you for your comment. The GC disagree with the view that a baseline cognitive assessment is required in addition to an assessment of adaptive function in this group. They agreed that this would require significant additional resources, and is not

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		Islington NHS Foundation trust				an age guidance to this to the recommendation.	necessary to assist diagnosis of dementia as the declining function associated with dementia is captured well by adaptive function measures. Therefore we will not be making this amendment. The GC also noted that this information should already be available and therefore were concerned that adding an age guidance to this recommendation may lead to such assessments not being documented early enough.
349		Islington Learning Disability Partnership, Camden & Islington NHS Foundation trust	Full	108	general	Advice to add CAMDEX assessment	The evidence for the CAMDEX tool was reviewed (see section 4.5.2 of the full guideline) and no studies were identified that met our criteria for inclusion. Therefore we were unable to recommend this tool.
350		Islington Learning Disability Partnership, Camden & Islington NHS Foundation trust	Full	General	General	We would welcome an addition about Care Programme Approach and 'how to apply this in LD services' as this the CPA criteria apply to the majority of LD patients with Mental health problems.	Thank you for your comment. The GC noted that CPA is implemented differently across the country and is specific to secondary MH services, therefore they decided that it would be helpful to reference it. Care coordination is the subject of section (1.2) of the short guideline.

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351	SH	Islington Learning Disability Partnership, Camden & Islington NHS Foundation trust	Full	156	General	Possibility of addition regarding need for access of patients with learning disabilities to specialised psychotherapy services: as for instance Dialectical Behavioural Therapy etc. would be helpful to clinicians.	Thank you for your comment. The evidence for a range of psychological therapies was reviewed, however no good quality evidence was found that would allow the GC to recommend any interventions other than those listed within the recommendations. Please see section 5.2 of the full guideline for the full review.
352	SH	Islington Learning Disability Partnership, Camden & Islington NHS Foundation trust	Full	293	72	**''All people with learning disabilities and a serious mental illness should have a key worker who:''** We wondered how feasible this is within MHLD or integrated LD services which is of course depending on the capacity and severity of cases within the team.	Thank you for your comment. This is an issue that we considered carefully. The keyworker role is one that is mentioned within NHS England's Transforming Care document. The GC felt that given the complex needs of many of these service users and the fact that involvement with multiple services is the norm, a key worker is an efficient and cost-effective way to ensure that service users are able to access the services and interventions laid out in their care plans.
353	SH	Islington Learning Disability Partnership, Camden & Islington NHS Foundation trust	Full	General	General	**Suggestion:** addition of the consultation role of Learning Disability Services supporting general services provide the best possible care to people with learning disabilities: support in making reasonable adjustments, offering accessible information advice, providing liaison	Thank you for your comment. The consultation role of learning disability services is covered in section 2.6 of the full guideline as well as within recommendation 1.8.1. The coordination role is covered by the recommendation to provide a keyworker within recommendation 1.2.8.

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						/coordinating role between services advocating for our patients.	
354	SH	Islington Learning Disability Partnership, Camden & Islington NHS Foundation trust	Full	General	General	Suggestion: In addition to the general increased risk of developing mental illness to highlight (create awareness of) the increased vulnerability/risk of patients with learning disabilities to develop mental illness around physical health problems (surgery), perinatal settings (pregnancy/delivery) etc. Which means additional support and awareness would be advised/ required around these important life events from all professionals involved.	Thank you for your comment. We agree that people with learning disabilities are at risk of developing mental health problems in relation to physical health problems, just as people within the general population are. This is reflected in recommendation 1.2.9.
355	SH	RCGP	Short	General	General	A thoughtful document based on expert opinion and demonstrating the lack of knowledge about the size and shape of the problem and the effectiveness of treatments or even how to measure. The recommendations are entirely sensible and appropriate.	Thank you for your comments. The GC agreed that to fail to include people with learning disabilities in RCTs is an exclusion issue, and that to take this course diminishes the evidence base.

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						Research is given priority but there are considerable ethical problems in conducting RCT's in populations where understanding and consent can be problematic. The first consideration should be detailed epidemiology (age, sex, race, social class, mental illness type, degree of illness and natural history) of the mental illness with underlying MH diagnosis where available and the profundity of that mental health. (PS)	
356	SH	RCGP	Short	12	13	1.5.5. Ideally there should be a single point of contact for referrals for mental and learning disabilities services for adolescents and adults as there often difficulties with boundaries between the services which can result in significant delays in getting specialist help as the GP tries to negotiate between CAHMS, the CLDT and Mental health services. (MH)	Thank you for your comment. The GC agree that access to services, particularly for adolescents and young adults, can be a real difficulty. This is an issue that was raised within the GC meetings, however referral pathways are a local implementation consideration, and beyond the scope of this guideline.

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357	SH	RCGP	Short	12	19	1.6.1 There are no guidelines for timescale for secondary services to see someone with a learning disability. This is often presents as a crisis and the person has to wait for a weekly allocation meeting before the referral is considered. (MH)	Thank you for your comment. The GC agree that access to mental health services is a serious issue nationally. This issue, however, is beyond the scope of this guidance.
358	SH	RCGP	Short	14	1	1.6.6. The person should be seen for a short period without their carers in order to check if anyone is hurting or abusing them or they are the subject of other formats of disability hate crime. (MH)	Thank you for your comment, this requirement is already set out in revised recommendation number 1.8.2.
359	SH	RCGP	Short	16	5	1.6.12-1.6.18 there is no mention of anxiety even if there is not a reliable tool. The identification of anxiety in people with learning disability and autism is particularly difficult and they are frequently missed by carers and clinicians, primarily owing to communication problems. In severe and profound learning disability only behavioural symptoms can be assessed, and as a result many anxiety disorders	Thank you for your comment. The GC agree that identification of anxiety is particularly difficult in these individuals. However despite an extensive review of the evidence, no reliable tools were identified for use in people with learning disabilities to assist in the identification of anxiety. Therefore the GC were unable to make any recommendations on this. This is an area that has been suggested for research. Prevalence of anxiety within particular conditions is mentioned within the full guideline, however the GC agreed it would be unhelpful to single out a specific condition such as Williams syndrome within the

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						are misdiagnosed as problem behaviours. Similary Williams syndrome should specifically mention with increased prevalence of anxiety. (MH)	recommendations.
360	SH	RCGP	Short	19	3	1.7.1 Currently the DES for annual health checks only goes down to 14 years and over and does not inclade doing annual health checks. This recommendation will create an important improvement in the current services if the DES is changed as a result. (MH)	Thank you for your comment, we hope this guideline results in the positive change you describe.
361	SH	RCGP	Short	22	24	1.9.3 When starting psychotrophic medication the psychiatrist should indicate a length of time of treatment with an end date after which the treatment should be consider for careful withdrawal. (MH)	Thank you for your comment. This is covered within revised recommendation number 1.10.5.
362	IND	IND	Short	9	30	Whilst it states that the staff should assess the mental capacity of the person throughout, on Line 30 it	Thank you for your comment. The GC agree that there will be instances where these guidelines will not apply. As stated at the start of the guideline

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						says that staff should discuss the assessment process and treatment options etc. The use of **'should'** in the sentence suggests that staff should always do these things irrespective of the person's degree of disability and appears contradictory to 1.3.2. If the person has a profound intellectual disability with no expressive and receptive language, or very limited language, it would not be appropriate to communicate everything in section 1.3.3. directly to the individual and doing so may harm collaboration with the support staff/family members who may perceive that the clinician has no understanding of the nature of the person's disability. A thorough assessment of capacity **should** be conducted first and **if** the person has capacity to make a decision/or potentially has capacity then the assessment and treatment process should be discussed with the individual, otherwise, it is more appropriate to include the individual as much as	clinicians are expected to exercise judgement at all times, and recognise these situations where they arise. The word 'should' is used to indicate that it is the expectation that this will happen unless there is a very good reason for it not to. This comes in part, from feedback from our service user focus group reporting that clinicians often speak over them, and assume that they cannot participate in discussions and decision making. Understandably they reported experiencing this as distressing and disempowering. This aims to redress this balance. As effective communication is required in order to reliably assess capacity, we are concerned that to reverse the order of these two sections would cause greater confusion. Therefore we will not be making this amendment.

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						possible but not burden them with the amount of information suggested in 1.3.3. I think that this is what this section is trying to convey but the order of the sentences need rearranging differently to avoid confusion.	
364	SH	College of Mental Health Pharmacy	Short	22	11	**Specialist pharmacists** Pharmacists and healthcare providers must ensure that the activities of pharmacists are being focused on high-priority patients and populations on a consistent basis. Multi-centre studies to evaluate the clinical and cost effectiveness of 'specialist pharmacists' providing pharmaceutical care to the population with intellectual disabilities are required. Psychotropic medication use in this population can result in the following □ production of some side effects that may not be recognised as being related to the medication and may be difficult for the person	Thank you for your comment. No evidence was found that would allow the GC to make recommendations regarding the specifics of involvement of specialist pharmacists. In the context of the very limited evidence base for treatment in this population, the role of specialist pharmacists is not an area that the GC have decided to prioritise over others for research. We are not able to consider evidence from unpublished doctoral theses.

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						with intellectual disability to communicate □ possibility that these side effects may in fact be diagnosed as further psychiatric illness or a further behaviour disorder □ difficulty in communicating any potential side effects of psychotropic medication to the person with intellectual disability before any treatment starts Specialist Pharmacists with expertise in intellectual/learning disabilities (PWID) (Ref: Bernadette Flood PhD MPSI, unpublished thesis 2015 , Medication Use in the Care of People Ageing with Intellectual Disabilities and Behaviour Disorders: The Specialist Pharmacist and Quality Indicators School of Pharmacy and Pharmaceutical Sciences, TCD) The role of 'specialist pharmacist' in the care of PWID is a 'reasonable accommodation' in the care of this population. 'Specialist pharmacists' can provide the	

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						following: □ Clinical services e.g. provide specialist pharmaceutical care for PWID and their carers and provide clinical medicines management support to residential and supported housing for PWID. □ Liaison services e.g. collaborate with specialist health and social care to contribute to the co-ordination, oversight and auditing of health care issues and initiatives particular to ID, e.g. uptake of health checks, development of health action plans, psychotropic drug use and access to health services e.g. breast screening. □ Educational services in partnership with others e.g. specialist ID professionals, psychiatrists working in ID & people who use services and their carers, develop the skills and knowledge of primary care to manage the health, healthcare and health promotion needs of PWID. □ Leadership services e.g.	

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						provide support to GPs & other health care professionals e.g. community pharmacists, to improve the "health experience" and health outcomes for PWID.	
365	SH	College of Mental Health Pharmacy	Short	24	1	Just to add: It is a problem about how to categorise behaviours that challenge that do not cluster together to meet the criteria for a mental illness. Some studies have categorised them as mental illnesses and if included then the prevalence of mental illnesses in the LD population comes out as to be very high. This NICE Guidelines attempts to separate them with the findings that although the incidence of mental illnesses is higher than in the general population it is not in the order of magnitude to support the prevalence of psychotropic drug prescribing that is present.	Thank you for your comment.
366	SH	Home Group	Short	General	General	We have concerns over the consistency in implementing the standards, which will be dependent on the drive and passion leading the implementation in any given	Thank you for your comments, your feedback will be passed along to the NICE implementation team.

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						area. As a national organisation, we have noticed a differing quality of implementation of the Crisis Care Concordat in some areas.	
367	SH	Home Group	Short	General	General	We note that there may be some cost implications, but these should not be substantial.	Thank you for your comments
368	SH	Home Group	Short	7	20	We believe the recommendations around staff training and supervision may incur some costs.	Thank you for your comment. The GC agreed that any upfront costs are justified as training and supervision is necessary for the maintenance of an effective workforce, and may result in cost savings later on as a result of more efficient and effective care.
369	SH	Home Group	Short	16	4	We believe that the potential development of new assessment tools could also lead to cost implications.	Thank you for your comment, it is recommended that existing assessment tools are used.
370	SH	Home Group	Short	17	11	Another potential cost implication would be the development of any new risk assessment tools.	Thank you for your comment, the development of risk assessment tools has not been recommended.
371	SH	Home Group	Short	General	General	We feel the standards being developed will provide more consistency with statutory services nationally for people who require care and support.	Thank you for your comments
372	SH	Home Group	Short	General	General	We believe the recommendations are worded in a clear and	Thank you for your comments

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						accessible way to professionals. We cannot say whether this would be true for individuals who are not well-versed in some of the terminology.	
373	SH	Home Group	Short	26	14	Further to accessibility of the guidelines, we believe that the explanation of terms used in the guideline helps to overcome this potential barrier. This section also helps to minimise ambiguity for professionals who would be implementing the guidelines.	Thank you for your comments.
374	SH	Home Group	Short	General	General	We believe the recommendations have successfully identified all statutory and non-statutory providers including community and individual carers.	Thank you for your comments
375	SH	Home Group	Short	30	1	For Home Group, the recommendation that case identification tools for common mental health problems are developed would have a significant impact. This would be as the development of these tools may incur cost implications and are likely to necessitate a change in professional practice to	Thank you for your comment.

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						accommodation new tools. We support the principle of the development of these tools.	
376	SH	Home Group	Short	33	5	Additionally, the recommendation that there should be research into the treatment settings for psychosis in people with mild learning disabilities would also have an impact upon Home Group. We would welcome such research into the clinical and cost effectiveness of delivering treatment for psychosis within a learning disabilities service, compared with a generic mental health service. We would support increased collaboration between mental health and learning disabilities, particularly due to the high rate of co-morbidity (40%). This research recommendation would help to examine whether there is a positive case in terms of service user experience and outcomes for such provision. As a provider of both generic mental health services and learning disabilities service, this recommendation would impact	Thank you for your comment. Following further discussion the GC have decided to broaden this research recommendation, although this still addresses issues of service configuration and service user experience, which the GC agreed were very important. It now reads 'the experiences of people with learning disabilities and mental health problems in services'. The group agreed that the new research recommendation would be more likely to attract research funding, and would therefore have a greater chance of improving care and outcomes for this patient group.

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						upon Home Group.	
377	SH	Home Group	Short	5	10	The recommendation around organisation and delivery of support will be one of the most challenging to put into practice. This is because this will involve the development of a leadership team at a strategic level of a whole range of leaders including health, social care and education to implement robust care pathways. These groups will also be needed to distribute information and guidance across all relevant agencies, organisations, individuals and communities. It will involve the consistency of care, development of protocols and the establishment of effective partnerships. This will need a shift in current practice to enable this to be effectively implemented and operate as efficiently as possible.	Thank you for your comment. It is the aim of NICE guidelines to set standards for the best practice and organisation of services and therefore it is hoped that this guideline will indeed bring about change to improve services.
378	SH	Home Group	Short	5	26	The designated leadership team for care pathways should also seek to cover housing association related services.	Thank you for your comment. Whilst we agree that housing is an important issue with an impact upon mental health, the issue of housing and associated services is beyond the remit of this guideline because the guideline only covers NHS services. Accordingly we are unable to make these types of

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							recommendations.
379	SH	5 Boroughs Partnership NHS Foundation Trust	Short	1.6.18	General	We think it unusual that they mention dementia in this, as it is comprehensively covered in the NICE guidance for dementia and not really satisfactorily covered here. Point 1.6.18 refers to a baseline of adaptive skills which is fine, but what about baseline assessments of everything else? May be a wording issue.	Thank you for your comment. The GC decided to make a specific recommendation regarding those with dementia as this is a particularly important issue in those with learning disabilities. The GC agreed that a baseline assessment of adaptive functioning is sufficient to identify any decline in functioning, and that no other baseline assessments would be necessary.
380	SH	5 Boroughs Partnership NHS Foundation Trust	Short	General	General	No mention of CPA/care co-ordination	Thank you for your comment. The GC noted that CPA is implemented differently across the country and is specific to secondary MH services, therefore they agreed that it would be unhelpful to reference it. Care coordination is the subject of section 1.2 of the short guideline.
381	SH	5 Boroughs Partnership NHS Foundation Trust	Short	General	general	The guidance does not adequately address the issue of when specialist / mainstream services are to become involved. There is no mention of the Green Light Tool Kit or integrated care pathways, or reference to any documentation supporting access to mainstream services and the need for reasonable adjustments to be consider as a proactive feature of	Thank you for your comment. We believe that appropriate service involvement, care pathways and reasonable adjustments are all covered within the guideline. These issues are covered extensively within recommendations 1.2.1-1.2.3 (care pathways), 1.2.5, 1.7.5, 1.8.1, 1.8.3, 1.8.24 and 1.10.3 (service involvement), and 1.3.1 and 1.9.2 (reasonable adjustments). Reasonable adjustments are a legal requirement, and we would expect that services would already make these. We are unable to recommend specific tools, such as the Green

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						service delivery across health and social care providers	Light Toolkit, without having reviewed evidence for their utility. Additionally local service configurations will necessarily vary and so the GC deemed it unhelpful to specify a particular service without a specific reason (as in the cited recommendations above).
382	SH	5 Boroughs Partnership NHS Foundation Trust	General	General	General	With respect to interventions, only relaxation, CBT and graded exposure are referenced, with no mention of other approaches (for example: such as behavioural interventions where MH is expressed as behaviour; or EMDR for anxiety disorders and adults with learning disabilities, for which there is a developing literature) or reference to the fact that only these have been referred to presumably because of such limited evidence for LD population. In other areas where there is a more developed evidence base, there is little reference to it (e.g. what about the literature for CBT and psychosis and adults with LD?). We appreciate that NICE's role is to recommend based on evidence, but we suggest some	Thank you for your comment. Despite extensively reviewing the evidence for psychological interventions the evidence found was limited in both volume and quality. The evidence was strong enough to make explicit recommendations for CBT, graded exposure and relaxation only. Recommendation 1.9.1 refers the reader to specific guidelines for mental health problems within the general population, with instructions on how to adapt interventions for this group.

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						acknowledgement of the need to use other interventions based on general population research is necessary. Alternatively, one might suggest the view that without evidence to the contrary, accepted guidelines for interventions should be followed.	
383	SH	5 Boroughs Partnership NHS Foundation Trust	Short	General	General	The range of mental disorders referenced presents a limited perspective of presentation for people with learning disabilities. For example, we don't recall seeing any reference to Personality Disorders or associated literature. As clinicians, we often approach intervention this clinical cohort in the same way our colleagues do in the general adult mental health field (a theme emerging here in regard to application of psychological therapies), predominantly utilising a DBT approach which yields good clinical outcome, but is an area to be identified as requiring further research and clinical trials (and thus access to funding).	Thank you for your comments. Personality disorders were within the scope of this guideline, and the available literature was reviewed. Unfortunately no evidence that met our inclusion criteria was found for assessment structure or tools or psychological interventions of those with personality disorders and learning disabilities, and accordingly the GC were unable to make any recommendations specific to those with a personality disorder as well as learning disabilities as a result. We agree that given the overall lack of quality evidence in this population a number of areas need to be identified for research funding. The GC agreed however that the 6 high-priority research recommendations that have been identified are the areas that require the most urgent attention. Recommendation 1.1.1 requests that the reader use this guideline alongside those relating to specific mental health problems (this would include

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							personality disorders).
384	SH	5 Boroughs Partnership NHS Foundation Trust	Short	General	General	In regard to medication, there appears to be no mention of discussing side-effects with service users.	Thank you for your comment. This issue is covered explicitly in recommendation 1.3.3 and implicitly within 1.10.7.
385	SH	5 Boroughs Partnership NHS Foundation Trust	Short	1.9.7	General	Seems to contradict NICE CB recommendations which accept the use of antipsychotics for CB (where MH may be an underlying cause).	Thank you for your comment. We disagree that this recommendation is in contradiction to the challenging behaviour guideline which clearly states that medication should only continue to be prescribed "that has proven benefit" (see NG11 recommendation 1.8.6). We believe that this is mirrored in bullet point 1 of revised recommendation 1.10.8 ('…consider reducing or discontinuing long-term prescriptions of anti-psychotic drugs').
386	SH	5 Boroughs Partnership NHS Foundation Trust	Short	1.10.1	General	What about referring to the need to consider financial/employment/adequate levels of support as potential causes of MH problems, as we know they increasingly are; need to specify need to refer on?	Thank you for your comment. This issue is addressed within recommendation 1.2.9 and again within 1.8.6.
387	SH	5 Boroughs Partnership NHS Foundation Trust	Short	27	General	Sequencing error for Profound and Severe	Thank you for your comment. The glossary was organised alphabetically, which is why severe LD followed profound LD. The glossary terms have now been changed and now consist of 'learning disabilities' with 'milder' and 'more severe' as subheadings.

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388	SH	Royal College of Psychiatrists	Full	General	General	There is an assumption that social care staff are adequately trained in relevant aspects of working with people with ID. That is not the case universally, and many social service teams are now generic with no specialist skills. There needs to be a requirement for at least some specialism within social services.	Thank you for your comment. We are aware that LD services may be provided by social care or jointly with the NHS. In setting out the skills and knowledge required (recommendations 1.2.9-1.2.11), our approach is to identify competencies rather than particular staff groups. We believe this is a consideration related to local implementation.
389	SH	Royal College of Psychiatrists	Short	general	1.2.8	'Should' have a key worker- it is unclear if there is any relation to the CPA role of care coordinator. Many patients with serious mental illness may only see their psychiatrist as they live in a residential home with carers at all times. I am not clear about strength of evidence to justify use of 'should'.	Thank you for your comment. The key worker role may be taken on by the care coordinator, depending upon local service arrangements. This has now been made clear within the 'Terms used in this guideline' section. The recommendation is a 'should' as the GC agreed that in many cases, where service users are involved with multiple services, access to and coordination between services is extremely difficult and a single point of contact is required. Additionally, this recommendation is consistent with NHS England policy following Winterbourne View (https://www.england.nhs.uk/wp-content/uploads/2015/10/service-model-291015.pdf)
390	SH	Royal College of	Short	general	1.3.4	If an adult with ID has capacity to	Thank you for raising this important point. The issue of family involvement arose both through our service

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		Psychiatrists				consent to the particular issue at hand, I fail to see why there is an exhortation to involve family etc except in 'exceptional' circumstances.	user focus groups and through our carer representatives. The GC wished to emphasise that family involvement can often be very helpful, whilst acknowledging that the service user's wishes must be respected, and there may be circumstances where family involvement is not appropriate.
391	SH	Royal College of Psychiatrists	Short	General	1.5.2	What 'identification questions' are these?	Thank you for your comment. This refers to the identification questions included in any relevant NICE guideline on mental health problems that maybe relevant to that service user.
392	SH	Royal College of Psychiatrists	Short	General	1.5.5	What about bipolar disorder and severe depression with or without psychotic features? It may be worth mentioning that both these conditions fall within the "psychosis" label.	Thank you for your comment. The wording of this recommendation has now been amended to more clearly indicate the inclusion of these conditions by referring to 'serious mental illness' (revised recommendation number 1.7.5: 'refer people with learning disabilities who have a suspected serious mental illness…')
393	SH	Royal College of Psychiatrists	Short	12 34	13 16	There was some concern that specifying that psychosis and dementia being referred to a psychiatrist creates an impression that psychiatry is not involved with the assessment and treatment of their mental health problems, but is only involved with psychosis and dementia.	Thank you for your comment. Psychiatry was specified at this point as the GC agreed that a review by a psychiatrist would usually be necessary in this situation. Elsewhere within the guideline the word 'staff' has been used to indicate that a number of appropriately trained individuals could be involved, including psychiatry (see 'Terms used in this guideline').

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394	SH	Royal College of Psychiatrists	Short	12 34	1.6.1	The suggestion that first assessments be conducted in a place familiar to the person has benefits but is a change from usual practice – usually first assessments are done in clinic. Some aspects of the assessment include full referral history and medication aided by access to IT. Changing this to home visits has resource implications as it adds travel time. It also has practical implications in terms of access to IT. The phrase "professional with expertise....." needs to be defined.	Thank you for your comment. In many services it is already standard practice to conduct initial assessments in a place familiar to the person. This does not necessarily mean their home setting, but could, for example, be their GP surgery. The GC agreed that the benefit in terms of enhanced engagement, ensuing validity of the assessment and therefore greater likelihood of receiving appropriate treatment were worth the additional up-front resource in terms of time, and expect that this is likely to lead to cost-savings in the long run. The GC agreed that the phrase 'professional with expertise' is appropriate, and encompasses a range of competent staff groups depending upon local service configurations.
395	SH	Royal College of Psychiatrists	Short	general	1.6.6	Slightly puzzled about the absence of ICD10- after all, it is used worldwide and to advocate use of completely different classification systems, especially given the push to mainstream services, would be counter-productive. DC LD & DM ID are mentioned here. May be worth mentioning that	Thank you for your comment. This recommendation has been amended to include the ICD and DSM-5 (now recommendation 1.8.6: 'establish or review a diagnosis using a classification system such as DSM-5 or ICD-10 or those adapted for learning disabilities…')

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						for many people, particularly those within the mild range of learning disability, ICD & DSM are applicable. The key point s hat a standard system of classification should be used.	
396	SH	Royal College of Psychiatrists	Short	general	1.6.14	It implies mini PAS ADD is better than clinical interview, which is not the case. This needs clarification. Mini PASAD is mentioned here for diagnosis. While this may be helpful if the assessment is by someone with no or minimal specialist expertise in LD mental health, there is a danger that this will be interpreted as mini PASAD is the instrument of choice. That is not and should not be the case. The gold standard is a full clinical examination by someone with an expertise in that area (e.g.: the specialist ID Psychiatrist). We shouldn't end up with the perverse conclusion that diagnosis is valid only if PASDA is used. Let us not forget that PASAD was validated	Thank you for your comment. We have now removed the mini PAS-ADD from this recommendation.

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						using the clinical interview as the gold standard	
397	SH	Royal College of Psychiatrists	Short	General	1.6.18	Not sure about need for routine baseline assessment of functioning in Down syndrome even before the age of high risk, especially as there are newer diagnostic tools that do not need serial assessments.	Thank you for your comment. The GC agreed that a baseline adaptive functioning assessment is helpful in identifying the skill loss commonly seen in people with dementia and that this is a particularly important consideration for this group. They agreed that this needed to be formally documented before the age of high risk in order to minimise the risk that decline had already begun, and facilitate early identification. They also agreed that as this information will often be available anyway, that this is a reasonable requirement. As we did not find any evidence for newer diagnostic tools that have been tested in this population we cannot comment on their suitability.
398	SH	Royal College of Psychiatrists	Short	General	1.7.4	Following Glover's study of use of psychotropic medication in primary care without a diagnosed mental illness, it would be helpful for GPs to review its use (either themselves or in conjunction with secondary services) during the annual health review.	Thank you for comment, the review of medication is included in recommendation number 1.6.3.
399	SH	Royal College of Psychiatrists	Short	22 34	26 1.9.3	At present clinical judgement and knowledge is used to determine	Thank you for your comment. This wording has been amended to address the point you have raised and bullet point 2 of revised recommendation number

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						when another consultant needs to be consulted with before a medication is started. The reasons for this include the significant proportion of patients requiring medication for a comorbid physical disorder and the delay the need to consult can build into the system – eg a patient recently had a delay of a month before starting an appropriate antidepressant due to the need to consult with her cardiologist. Making this a requirement in less complex situations where the clinician feels competent to prescribe (bearing in mind psychiatrists in learning disability often have experience with and knowledge of anticonvulsant medication and epilepsy) will have implications for workload, for delay in timely treatment and for workload of colleagues, particularly neurology if they are asked to consult in situations where currently they are not.	1.10.4 now reads 'where necessary consult with specialists…'

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						Increase in costs challenging to implementation of this recommendation. "Consult" with others (explain further).	
400	SH	Royal College of Psychiatrists	Short	general	1.9.7	The definition of psychosis becomes important again as referred to in the comment on 1.5.5. Bipolar and severe depression have to be included here. (Let us not forget that the antipsychotic Quetiapine is mentioned as the treatment of choice for depression in bipolar illness within the NICE guidelines for bipolar disorder).	Thank you for your comment. The wording has been altered for clarity (revised recommendation number 1.10.8: 'for people with learning disabilities who are taking antipsychotic drugs and not experiencing psychotic symptoms…').
401	SH	Royal College of Psychiatrists	Short	General	1.11.3	Consider' practical support- the ownership of these interventions could be clearer – although there may not be clear evidence for use of these interventions, this ought to be a specific consideration for social services.	Thank you for your comment. This is an implementation consideration, will vary according to local service configurations and is beyond the remit of the guideline.

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402	SH	Royal College of Psychiatrists	Full	general	6.1	Paragraph 2 says that, broadly speaking, people with learning disabilities are prescribed psychotropic drugs including antipsychotics in 2 sets of circumstances: either because they have a psychiatric diagnosis or because they have behaviour that challenges (NICE, 2015). An additional sentence has to be inserted here- These two groups are by no means mutually exclusive. That point is made clear in the subsequent paragraphs, but an explicit statement at the beginning would make the point clear.	Thank you for your comment. We have now amended the wording to make this point clearer and it now reads 'either because they have a psychiatric diagnosis, because they have behaviour that challenges or both'.
403	SH	Royal College of Psychiatrists	Full	196	30 34	Are the Guideline's comments suggesting that those on anticonvulsant or with other comorbid physical health conditions, and prescribed psychiatric medications, are reviewed routinely every 3-4 weeks, or just at treatment initiation or when doses are changed?	Thank you for your comment. These bullet points describe the statements that were endorsed by the GC using the nominal group technique. Both statements were endorsed, however upon further discussion the GC decided not to impose a time limit. The wording within the statements 'The GC endorsed statements stating that' and LETR table 'Although the GC initially endorsed statements calling for specific timescales for review of medications (see clinical evidence statements), they

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						Are they also suggesting that people prescribed psychiatric medications are reviewed every 6 weeks? Are they including those on long term medication who are stable? This has very considerable resource implications if this is the case and at present would not be possible to deliver without a very large increase in resources and would involve a new service to allow such reviews – probably involving nursing reviews supervised by psychiatry as is done in the case of Clozapine and Lithium.	decided upon discussion that this should be dependent upon the individual and their circumstances. Therefore they did not make a specific recommendation on this.' has been made clearer. The GC agreed that medication should be reviewed regularly, and that this is crucial for safe and effective care. Our service user focus groups also expressed concern that people are often placed on medication and this is not monitored appropriately. We believe on this basis that any increase in resource use is justified.
404	SH	Royal College of Psychiatrists	Full	276	36 40	There are downsides to it which are not mentioned, including difficulties with the environment of generic wards for people with more severe learning disabilities and those with autism and the vulnerability of people with learning disabilities on	Thank you for your comment. The issue of the most appropriate setting for inpatient treatment was discussed extensively by the GC and the points you mention were raised. The fact that these have not been listed here is an omission, and we have now stated this within the LETR section in the full guideline. The problem of people travelling across the country, which as you will be aware is the

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						generic wards. One of the problems I assume this seeks to address is of people with learning disability who are admitted having to travel so far to get to a specialist unit.	subject of an NHS England initiative, did indeed feature heavily in our GC discussions and this fed into the development of these recommendations. This is also described within the LETR section.
405	SH	Royal College of Psychiatrists	Full	281	44	There could be some problems with facilitating a preference for workers of a particular culture where this could be seen as condoning prejudiced attitudes. It might be better to change the possible for "appropriate" and "where there are good reasons".	Thank you for your comment. Whilst we appreciate your concern, we believe that this is an issue of equality and patient choice, and to subject a service user to judgements about the reasons for this may deter people from accessing services.
406	SH	NDTi	short	5	12	Our work on the Green Light Toolkit indicated that having a champion or liaison nurse in mental health services was an important factor in enabling mental health services to make the reasonable adjustments required so that people with learning disabilities could use them. For further information see: http://www.ndti.org.uk/major-	Thank you for your comment, there are a number of ways in which services will achieve the implementation of this guideline and make reasonable adjustments to services to make those services accessible for people with learning disabilities.

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						projects/current/green-light-toolkit-2013/	
407	SH	NDTi	short	5	23	Currently there are often arbitrary eligibility criteria regarding access to some mental health services for people with learning disabilities. Some CAMHS don't accept young people with learning disabilities, and some adult mental health services don't either – often because of historical patterns of care. I think this should be acknowledged here – and every effort should be make so that these services are accessible. Areas should map eligibility to ensure that all groups requiring mental health services have access to them locally (whether through CAMHS or adult mental health services).	Thank you for your comment. Concerns over access to services and people 'falling between the gaps' were considered at length by the GC. We have attempted to address this throughout section 1.2 on organising effective care, in particular in recommendation 1.2.5.
408	SH	NDTi	short	9	15	See also the Five good communication standards developed as part of the Concordat Commitments http://www.rcslt.org/news/docs/good_comm_standards	Thank you for your comment, it is not NICE policy to refer to other standards within the recommendations as the evidence for these has not been reviewed.
409	SH	NDTi	short	17	14	What about risk to quality of life? So need to take into account	Thank you for your comment. The GC agree that whilst risk management is important, it is important

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						positive risk taking rather than just preventing harm.	to take a proportionate view of risk. This is covered by recommendation 1.8.19.
410	SH	NDTi	short	24	14	Need to add – that people with learning disabilities should be given support to develop friendships and relationships – as an important protective factor re poor mental health Also need to consider the risk of bullying and hate crime when considering where people live. Is the area relatively safe? Is there a safe places scheme etc?	Thank you for your comment. This issue was discussed extensively by the GC, who agreed that it was important to give people the opportunity to develop relationships if they wish, but not to force this upon them. The wording of recommendations 1.5.1 and 1.5.2 were chosen to reflect the provision of opportunities within this context. Similarly, we agree that bullying and hate crime are important issues and would factor into a supported decision on living arrangements, however the GC wanted to stress that people should be supported to make that choice themselves.
411	SH	NDTi	short	24	19	Supporting people to have a healthy lifestyle as diet and exercise can also be important factors	Thank you for your comment. Evidence on dietary and physical exercise interventions to prevent mental health problems was inconclusive and therefore the GC were unable to recommend these. However, encouraging people to have a healthy lifestyle, and the provision of advice about diet and exercise, is one of the functions of the annual health check (see section 1.6).
412	SH	NDTi	short	25	14	Day centres may play a role but they are not local community resources – needs to be a separate point	Thank you for your comment. We have now amended revised recommendation number 1.11.1 in line with this. It now reads *'…access local community resources, such as libraries, cinemas, café's and leisure centres'*.

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413	SH	NDTi	short	General	General	There could be a stronger focus on prevention right from the start by a focus on tackling health inequalities, which is implied but not made specific in the document. We know that people with learning disabilities experience health inequalities and that this has an impact on their health, including mental health. The determinants of health inequalities need to be addressed from an early age to mitigate the impact. Evidence on the health inequities experienced by children with learning disabilities can be found here: https://www.improvinghealthandlives.org.uk/publications/313899/The_determinants_of_health_inequities_experienced_by_children_with_learning_disabilities The document notes that Health and Wellbeing Boards should know about children with learning disabilities through Joint Strategic Needs Assessments and put programmes in place to reduce child poverty locally, reduce exposure to specific hazards and	Thank you for your comments. The relationship between factors such as child poverty and poor mental health is well-documented, and is a factor that the GC were aware of. However this is an issue that was not within our scope. NICE are charged with making recommendations relating to health and care settings, and it is beyond our remit to recommend the types of interventions you suggest here.

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						increase resilience. Ensuring the needs of children and adults with learning disabilities are in JSNAs and that Health and Wellbeing Boards have plans in place as above are important preventive measures	
414	SH	NDTi	Short	General	General	It would be helpful to include the Green Light Toolkit in the resources section of the guidance.	Thank you for your comment. We are unable to recommend particular tools such as the Green Light toolkit without having reviewed evidence for its utility.
415	SH	British Association of Art Therapists	Full	156	5.2.7.1	First recommendation – to use NICE guidelines for specific mental health problems. Whilst helpful, this will miss studies specifically on art therapy for people with learning disabilities, which may not be covered under guidelines for specific mental health conditions. Please refer to the British Psychological Society document: "Psychological therapies and people who have intellectual disabilities": BPS, February 2016 - membernetworkservices@bps.org.uk	Thank you for your comment. The evidence for a range of complimentary therapies was reviewed, however no good quality evidence was found that would allow the GC to recommend art therapy specifically as a treatment modality.

Registered stakeholders:

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None of the stakeholders who comments on this clinical guideline have declared any links to the tobacco industry