NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

HEALTH AND SOCIAL CARE DIRECTORATE

QUALITY STANDARD CONSULTATION

SUMMARY REPORT

1 Quality standard title

Care and support of people growing older with a learning disability.

Date of quality standards advisory committee post-consultation meeting:
9 April 2019

2 Introduction

The draft quality standard for Care and support of people growing older with a learning disability was made available on the NICE website for a 4-week public consultation period between 11 February and 11 March 2019. Registered stakeholders were notified by email and invited to submit consultation comments on the draft quality standard. General feedback on the quality standard and comments on individual quality statements were accepted.

Comments were received from 23 registered stakeholder organisations, which included service providers, national organisations, professional bodies and others. 1 non registered stakeholder and 1 individual also submitted comments.

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

Consultation comments that may result in changes to the quality standard have been highlighted within this report. Comments suggesting changes that are outside of the process have not been included in this summary. The types of comments typically not included are those relating to source guidance recommendations and suggestions for non-accredited source guidance, requests to broaden statements out of scope, requests to include thresholds, targets, large volumes of supporting information, general comments on the role and purpose of quality standards and requests to change NICE templates. However, the committee should read this summary alongside the full set of consultation comments, which are provided in appendices 1, 2 and 3.

3 Questions for consultation

Stakeholders were invited to respond to the following general questions:

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

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

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

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

4 General comments

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

- The quality standard was welcomed and well received.
- Most stakeholders thought that the draft quality standard accurately reflected areas for quality improvement.
- The stakeholder that didn't think the draft quality standard accurately reflected areas for quality improvement suggested alternative areas.
- Stakeholders were pleased to see recognition in the Equalities Impact Assessment that implementation of the statements relies on good communication.
- Concerns were raised that it was not clear how supporting people with a learning disability differs from supporting anyone else as they grow older.
- Acknowledgement that defining a specific age group is a challenge but concern that lack of clear definition of "people growing older with a learning disability" would make implementation, monitoring and benchmarking very difficult.
- Suggestion that support for carers should be considered within the quality standard and carers' views should be included within the measures.
- Suggestion that autism should be included within this quality standard.
- Easy read versions should be simplified and co-produced with people with a learning disability.
- The NHSI Learning Disability Standards are included in the NHS Long Term Plan. The standards are supported by an improvement tool which is about to be launched. The NHSI Learning Disability Standards will be included in NHS Benchmarking Network data in the future but contributing to this is voluntary and used by providers for internal quality improvement and benchmarking.

Consultation comments on data collection

- Concerns were raised about the complexity of measuring impact and meaningful involvement.
- Most of the data is not currently collected.
- April 2011 - the Single Data List replaced the National Indicator Set reducing the number of data returns for local government to submit to central government. Councils do not have to provide anything that is not on the list, unless extra funding is provided.

Consultation comments on resource impact

- Capacity issues in learning disability nursing – serious workforce decline since 2010 was highlighted.

5 Summary of consultation feedback by draft statement

5.1 Draft statement 1

People with a learning disability are actively involved when their care and support needs are being assessed.

Consultation comments

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

- The person with a learning disability should have an opportunity to prepare for the assessment.
- Communication methods need to be specific to each person to ensure effective communication and support decision making.
- The statement should emphasise promoting better health and wellbeing.
- The assessment should cover capacity and best interest decisions.
- The assessment should consider loneliness and social exclusion.
- Faith and cultural considerations should be mentioned.
- The role and importance of working with carers and the persons' support circle should be highlighted; they should be treated as equal partners in care as they have the information necessary to provide care and support.
- Independent advocacy should be more prominent in this statement; as people get older, they are less likely to have a family member who supports them.

Consultation comments on resource impact

- Staff require time, accessible information materials and training to effectively involve people with a learning disability.

5.2 Draft statement 2

People with a learning disability have a named lead practitioner responsible for coordinating their care and support.

Consultation comments

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

- The person with a learning disability should have a choice about who their named lead practitioner is.
- There is an opportunity to build this approach into the development of Primary Care Networks and more proactive and preventative local work on frailty.
- Information sharing between services is not well established which makes the role of lead practitioner very difficult.
- Lead practitioners can come from various backgrounds which may determine what information they get access to.
- Changes to services and improved integration of health and social care are necessary before implementation becomes realistic.

Consultation comments on resource impact

- Concern that the statement is not achievable within the limitations of current capacity.
- Specialist training is needed for people to become a lead practitioner.
- National implementation and nationally commissioned resources are needed to support practitioners in their role.

5.3 Draft statement 3

People with a learning disability have a plan for the future that is reviewed at least annually.

Consultation comments

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

- It is important for people to be involved in planning throughout their lives, and it must not be left until a person starts to lose ability or capacity.

- This plan should include considering the way to lead an inclusive lifestyle, develop and sustain relationships, including sexual relationships.
- There is a need for increased knowledge for individuals with a learning disability and family carers regarding what changes they may experience and what specific support they may need.
- The role of carers and the person's support circle in making plans for the future should be emphasised.
- The plan should recognise mutual caring and planning for the future within that context as well as planning for the time when the parent is no longer there.
- Important to be included in QOF, local audits, quality improvement work, current and future digital technology and innovations to help keep people safe in their community.
- Specific age, criteria or a trigger point is needed to make this statement more realistic for implementation.
- Additional elements suggested for inclusion in plans for the future were:
  - oral health needs
  - environmental changes beyond leaving the current home
  - high quality end of life care
  - funeral planning.

5.4 Draft statement 4

People with a learning disability have their health action plan updated after every annual health check.

Consultation comments

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

- Implementation of the statement relies on the extent to which GP practices engage with the NHS LD Health Check Scheme.
- The statement should concentrate on quality of the health checks and how they are used to address the specific needs of older people.
- The statement should focus more on social issues and social isolation rather than physical health and health services.

- Additional elements suggested for inclusion in health checks and health action plans:
  - mental health and wellbeing
  - medication review and alternative treatment options
  - social prescribing
  - dentistry and oral health needs
  - dementia
  - pain management.

5.5 Draft statement 5

People with a learning disability meet with hospital staff before any planned hospital stay to agree reasonable adjustments which would make the stay easier for them.

Consultation comments

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

- Suggestion to extend the statement to cover unplanned hospital admissions and hospital discharge.
- The statement should facilitate improvements to discharge procedures – including a good understanding of different types of support required – homecare, supported living, residential care homes, nursing homes.
- The statement needs to put stronger emphasis on addressing the communication requirements of each individual.

6 Suggestions for additional statements

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

- Sedentary behaviour and TV watching in adults with a learning disability - providing educational and physical activity programs as well as social networking
- Polypharmacy and psychotropic medication in adults with a learning disability
- Annual flu vaccination and 5 yearly pneumococcal vaccination.
- Adequately resourced community learning disability teams embedded in primary care settings
- Learning disability liaison staff in hospitals and hospices

- Dementia care
- Safeguarding
- Staff training

Appendix 1: Quality standard consultation comments table – registered stakeholders

ID	Organisation name	Statement No	Comments
1	Association for Family Therapy and Systemic Practice - UK	General	We welcome the intention to actively involve people living with learning disabilities in assessing and planning their lives and futures, and appreciate the thought given to the additional support needed to meaningfully involve people who are living with learning disabilities which are severe or profound.
2	Association for Family Therapy and Systemic Practice - UK	General	Families and carers may have additional needs of their own and it would be useful to consider whether they might need additional support in order to be able to support the involvement of the person living with learning disabilities. Those with up to date carer's assessments might have additional support needs identified this way, however sometimes needs may be of a more fluctuating nature (e.g. variable stresses, load demands and mental health issues) which may need extra time and negotiation to organise meetings to allow family / carer involvement to go ahead.
3	Camphill Families & Friends.	General	We are a charitable organisation of many years standing, comprising the families of people with learning disabilities who live in Camphill Communities, of which there are more than twenty in UK and which follow the principles of Dr Rudolph Steiner. These principles strongly assert that the individual with learning disabilities is on a par with people without learning disabilities and deserves all the support needed to enable the individual to have a full, active and fulfilling life as similar as possible to that of his/her non-disabled relatives. One of the best ways of achieving this is to set up special communities in which these principles are followed. Families are profoundly grateful to Camphill for providing such a life and such communities.
4	Carers Trust	General	Carers should be included as a data source for evidence through out the Quality Measures. Carers Trust are pleased to see that NICE have set out measures within the Quality Standards that will support carers, and encourage providers to involve carers in care and support planning. Given this, carers' views should be sought as part of the process to evaluate and measure the success of these Quality Statements. Carers will have valuable information both about the support they have received, as well as insights into the care and support received by the person with learning disabilities that they care for.

5	Down Syndrome Association	General	We celebrate that many individuals with learning disability, especially adults with Down's syndrome have improved life expectancy (50-60 years now, compared with 40-45 20 or 30 years ago. However average life expectancy of adults with a learning disability is still nearly 30 years younger than for those without a learning disability.
6	Family Planning Association	General	The development of loving relationships is an important and valued part of adult life, which many people with disabilities say is important to them. People with disabilities have the right to sexual health and wellbeing and the right to be acknowledged as sexual beings. Despite this, the sexuality of people with disabilities is often ignored, neglected or stigmatised by society. There is limited research regarding the number of people with learning disabilities in a relationship, however evidence from 2005 suggests just 3% of adults with learning disabilities are cohabiting, compared with 70% of the general population.[1] There are many barriers to good sexual health and wellbeing for people with disabilities, this includes, poor understating of sex and relationships; the balance between rights and risk which is often skewed towards the restriction of choices; and social attitudes leading to alienation, stigma and discrimination We believe the quality of life of people growing older with a learning disability, specifically in terms of sexual and non-sexual relationships as well as social inclusion, should be reflected and acknowledged within this guidance. Whilst we appreciate the reference to sex and relationships through the reference to NG96 1.3.5 within Quality Statement 1, this could be clearer. There is also an opportunity to reference sex and relationships in the section on planning for the future and Health Action Plans, which should involve talking about sex and relationships. [1] Emerson, E., Malam, S., Davies, I. and Spencer, K. (2005) Adults with Learning Disabilities in England 2003/4
7	Local Government Association (LGA)	General	There is no mention of autism in the quality statements or draft. Care and support services for people with learning disability and autism are often closely aligned at a local level and this should be recognised in the guidance. Also page 2 should refer to NICE guidance on Autism and adults - QS51 https://www.nice.org.uk/guidance/qs51

8	Local Government Association (LGA)	General	The draft does not mention Sector-led improvement (SLI). SLI is the approach to improvement put in place by local authorities and the LGA alongside the abolition of the previous national performance framework. SLI is based on the underlying principles that local authorities are: • responsible for their own performance • accountable locally, not nationally • there is a sense of collective responsibility for the performance of the sector as a whole, and • the role of the LGA is to provide tools and support. Further Information: https://local.gov.uk/our-support/our-improvement-offer/what-sector-led-improvement
9	Local Government Association (LGA)	General	Page 2 should also mention the following NICE Quality Standards publications: QS123 Home Care for older people. QS 137 Mental wellbeing and independence for older people QS 50 Mental wellbeing of older people in care homes
10	Manchester Metropilitan University	General	It is important that care and support is improved for older people with learning disabilities.
11	Manchester Metropilitan University	General	All 5 quality statements are important to achieve – for all people with learning disabilities, not just older people. People with learning disabilities have been saying they want to be actively involved, have a named lead practitioner etc for a long time.
12	Manchester Metropilitan University	General	Most of these statements are already supposed to be happening for people with learning disabilities – however, they often do not happen for many people. What will change to make sure they happen now?

13	NHS England	General	No specific comments. In general, the standard makes sense and the principles are important. In primary care, there will be a mix of adoption of this standard. Some practices will be very good and engage most of their patients who have learning difficulties. Other practices may not be doing so and education and training will be needed. Whilst the development of primary care networks should improve the consistency of the service, it is also important not to lose the continuity of care. This is especially important as this group of patients are likely to benefit from seeing clinicians they already have a relationship with. This is an area CCGs will need to consider when commissioning services, with consideration of the E+D aspects and potential difficulties in communication. Coordination of care is similarly varied, usually with a named GP but unclear how this feeds into the patient's care itself. Reviews are likely to occur annually, but measuring the value of these is difficult – I am not sure that they will all be of good quality or feed into improving patient care. This would also apply with QS4 (health action plan) – it is likely these are being considered but the actual impact/ outcome measures aren't really there. We can't be sure how effective we are being. Again, QS5 feels the right thing to be doing and is done well in some areas. Overall, the proposal makes sense and has the potential to improve both the experience and quality of care patients receive. My main comment would be how we ensure any reviews etc are in fact of benefit. Ticking a box to say a review has been done does not mean it has been in the least effective. (GW)
14	NHS England	General	As a comment – there is inconsistency in terminology throughout this document. 'learning difficulties', 'learning disabilities', 'a learning disability' In NHSI Learning Disability Standards: this is included in the NHS Long Term Plan with the standards supported by an improvement tool about to be launched. The NHSI Learning Disability Standards will be included in NHS Benchmarking Network data in the future but contributing to this is voluntary and used by providers for internal quality improvement and benchmarking. (JOH)

15	Royal College of Speech and Language Therapists	General	The RCSLT is pleased to see recognition in the Equalities Impact Assessment that standards 1, 2, 3 and 5 rely on good communication and this should be explicitly considered during the development of the QS. People with a learning disability with communication difficulties will need additional support to maximise their understanding and engagement in decision making. Support from a speech and language therapist will support better and more effective communication.
16	Royal College of Speech and Language Therapists	General	The easy read information still appears very text-heavy with limited visual support actually relating to the content of the statement. It is unclear whether people with learning disabilities were involved in the production of this information; in fact it is unclear who was consulted on this. While the RCSLT support provision of easy read information on all guidance and standards, we would support full co-production of these resources with the target audience.
17	Skills for Care	General	In terms of the 5 statements, they would seem to be equally relevant to all people with a learning disability, not specifically older people.
18	Skills for Care	General	We are not sure the standard captures the essence of what is different about supporting an older person with a learning disability as opposed to supporting older people generally or anyone with a learning disability.
19	Skills for Care	General	In terms of measurability, some of them may be quite difficult to measure. For example the statement about actively involved looks at the proportion of people who were actively involved versus the number of assessments undertaken. This isn't going to reflect how many people were not able (or declined) to be actively involved. Similarly the standard about measuring the plan for the future is just measuring people have a plan, not how meaningful or person centred that plan is.
20	Dimensions	Question 1	Yes, the draft quality standard accurately reflects areas for quality improvement.

21	Royal College of General Practitioners	Question 1	These draft quality standards do not adequately reflect the key areas quality improvement. These should include: 1. tackling sedentary behaviour and TV watching in adults with learning disabilities, and providing educational and physical activity programs as well as social networking 2. tackling polypharmacy and psychotropic medication in adults with learning disabilities by GPs, practice pharmacists and psychiatrists in community learning disability teams 3. introducing dementia care mapping 4. ensuring hospitals and hospices have learning disability liaison staff 5. ensuring that community learning disability teams are adequately resourced and provide ongoing support rather than just crisis care 6. embedding community learning disability teams in primary care settings 7. ensuring all adults with learning disabilities are offered an annual flu jab and 5 yearly pneumococcal vaccination as pneumonia has been identified as the commonest cause of death in this group by Learning Disabilities Mortality Review (LeDeR) Programme
22	Royal College of Nursing	Question 1	Does this draft quality standard accurately reflect the key areas for quality improvement?- Yes it does.
23	The Dirac Foundation	Question 1	Addressing “Does this draft quality standard accurately reflect the key areas for quality improvement?” Assuming that the question is also about key areas, my concern here is in regard to patient comprehension and compliance enhanced by standard simple forms of labels and instruction leaflets with canonical images for those with learning disabilities, difficulties with English, or stroke/damage to the phonetic part of the brain, for use of which principles of EBM, Comparative Effectiveness Research and Outcomes analytics could readily be applied. The notion is not a complex academic issue - See attached image. Also see “using visual concept mapping to communicate medication information to chronic disease patients with low health literacy” Lilian H. Hill and Mary M. Roslan Concept Maps: Theory, Methodology, Technology roc. of the First Int. Conference on Concept Mapping A. J. Cañas, J. D. Novak, F. M. González, Eds. Pamplona, Spain 2004, and Hwang SW, Tram CQ, Knarr N (2005) The effect of illustrations on patient comprehension of medication instruction labels. BMC FamPract 6: 26., and Katz MG, Kripalani S, Weiss BD (2006) Use of pictorial aids in medication instructions: a review of the literature. Am J Health Syst Pharm 63: 2391-2397.. I do note in the NICE draft document "They may also use augmentative and alternative communication approaches such as manual signs, pictures, objects

			and aids to help people to communicate well" in the document but that does not in my view go far enough, and it must be asked as to what EBM and comparable principles are actually being applied to this. I still think that this is a very key area in the scope of this topic, but unless the ruling has been recently modified on 10 years (inappropriate in this case, I think) or related work has come to light as inquired below, I probably can't add anything to my comment sent earlier, i.e. "I really don't think that a 10 year limit on evidence from various countries is appropriate for this kind of consideration. This is not about, for example, large group or population studies a pharmaceutical drug.... An acid test question here is what more recent literature on pictorial concept map guidance and Bliss Symbolics within the last ten years has the NICE taken into consideration?. In view of the absence of relevant recent work, I would suggest that it is an area for quality improvement. I would suggest however that there are two recent articles that could fall into the category of acceptance https://bmcmedinformdecismak.biomedcentral.com/articles/10.1186/1472-6947-13-10 and https://bmcmedinformdecismak.biomedcentral.com/articles/10.1186/1472-6947-13-10 because they do contain points that represent objective research and impact or are readily adaptable to the above considerations, e.g. by replacing words on concept maps by images.
24	Local Government Association (LGA)	Question 2	The following data collection processes are in place at local authority level. The proposed quality measures are not currently collected – it would require further investigation to establish the feasibility of collecting such data with current systems and structures. However it is important to note that LGA is committed to reducing data reporting burdens on councils. NHS digital - Adult Social Care Outcomes Framework (ASCOF). ASCOF measures how well care and support services achieve the outcomes that matter most to people. The ASCOF is used both locally and nationally to set priorities for care and support, measure progress and strengthen transparency and accountability. Data sets include: • 1E Proportion of adults with a learning disability in paid employment • 1G Proportion of adults with a learning disability who live in their own home or with their family • 1 J Social care related quality of life • 1B The proportions of people who use services who have control over their daily life • 1C The proportions of users and carers who receive self-directed support, and those receiving direct payments • 3A Overall satisfaction of people who use services with their care and support

			• 4A Proportion of people who use services who feel safe • 4B Proportion of people who use services who say that those services have made them feel safe and secure Link: https://digital.nhs.uk/data-and-information/publications/clinical-indicators/adult-social-care-outcomes-framework-ascof/current#data-sets Adult Social Care Activity and Finance Report, England - 2017-18. This publication contains data taken from the Adult Social Care Finance Return (ASC-FR) and Short and Long Term (SALT) collection to provide information regarding adult social care activity and finance on local authorities in England for 2017-18. Includes information on activity levels detailing support setting by primary support reason. It also includes measures on accommodation and employment status of clients with a primary support reason of LD. The outputs are published here - https://digital.nhs.uk/data-and-information/publications/statistical/adult-social-care-activity-and-finance-report/2017-18 NHS Digital – Learning disabilities health check scheme. https://digital.nhs.uk/data-and-information/publications/statistical/learning-disabilities-health-check-scheme/england-quarter-3-2018-19 NHS Digital – Mental health services monthly statistics. NHS funded secondary mental health, learning disabilities and autism services in England. https://digital.nhs.uk/data-and-information/publications/statistical/mental-health-services-monthly-statistics NHS Digital health and care of people with learning disabilities. https://digital.nhs.uk/data-and-information/publications/statistical/health-and-care-of-people-with-learning-disabilities Public Health England (PHE) Learning disability health profile. https://fingertips.phe.org.uk/profile/learning-disabilities

25	Local Government Association (LGA)	Question 2	The LGA is committed to reducing data reporting burdens on councils. In April 2011 the number of data returns which local government were required to submit to central government was reduced when the National Indicator Set was replaced by the Single Data List. The Single Data List contains the entirety of central government departments' data requirements from local government, which means that councils know exactly what information Government will ask for over the course of the year. Councils do not have to provide anything that is not on the list, unless extra funding is provided. So resources would be required to deliver any further data reporting. Further information: https://www.local.gov.uk/our-support/guidance-and-resources/data-and-transparency/reducing-data-burden
26	Royal College of General Practitioners	Question 2	The definition of 'people growing older' is unclear. Without an age range this will not be able to be used to benchmarking or monitor standards across England and Wales.
27	Royal College of Nursing	Question 2	Whilst not being able to comment on this due to the local nature of services, however, we are aware there are not enough learning disability nurses in post, The Royal College of Nursing (RCN) has called for urgent investment in this area to attract more applicants into learning disability nursing as latest workforce data shows a 40% drop in specialist nurses since 2010.
28	NHS England	Question 3	We support the development of future care plans and review for individuals with learning disabilities. Thought is required to ensure these are shared across health and care settings, in order for them to be enacted across the care pathway (SC)
29	Royal College of Nursing	Question 3	We are unable to comment on this due to the local nature of services.
30	Association of Directors of Adult Social Services	1	Mention should be made of the relevance of involving advocates in the process -particularly given the likelihood that as people age they will have less direct family members able to assist in their care and support.
31	Association of Directors of Adult Social Services	1	A data source of use of advocates should be included
32	British Institute of Learning Disabilities (BILD)	1	Needs to include emphasis on promoting better health and wellbeing
33	British Institute of Learning Disabilities (BILD)	1	Recognition that family members will often be the experts in terms of knowledge of and ability to share best ways of communicating with the individual. Emphasis on working in partnership with family needs strengthening.

34	British Institute of Learning Disabilities (BILD)	1	Need to ensure seamless nature of person centred needs assessment and being proactive
35	British Institute of Learning Disabilities (BILD)	1	Need to identify ways in which to support individuals to make decisions and informed choices. Also needs to address how to maintain friendships and relationships. Also, access to advocacy and advocates.
36	British Institute of Learning Disabilities (BILD)	1	Emphasis on potential of circle of support and the wrap around team approach
37	British Institute of Learning Disabilities (BILD)	1	Faith and cultural considerations should be mentioned.
38	Camphill Families & Friends.	1	Some adults with a learning disability live in supported communities. Communities comprise not only formal communities of various types like Camphill but also informal communities, e.g. when people with learning disabilities share a life with one another as well as with supporters in shared or linked houses etc. In such cases there are often formed Circles of Support comprising friends, supporters (formal and informal), families and others (e.g. volunteers) who support and help in varying ways the lives of the learning disabled individuals, including decision-making. These Circles are extremely important to people with learning disabilities and play a large part in most aspects of their lives. They should be included in all planning and decision-making and mentioned as such. We recommend adding a specific acknowledgement that members of these communities – including staff – should therefore also play a role in assessing the care and support needs of a person with a learning disability who is growing older – alongside family members.
39	Carers Trust	1	Carers Trust welcome the inclusion of family members and carers to gather the necessary context and information. Carers Trust believe that carers should be treated as equal partners in care as they will often have vital information about the person with care and support needs.

40	Carers Trust	1	Carers Trust welcome this section which sets out what this statement means for carers. It is good to see NICE setting out that carers should be “involved in assessing the care and support needs of the person with a learning disability who is growing older”. It is also good to see that NICE is setting out the need to “recognise and review” carers’ roles in existing caring arrangements and that the guidelines set out the need for carers to have a carers assessment to ensure they get the support they need. Carers Trust welcome the inclusion of the need to recognise “mutual caring arrangements”. Mutual caring arrangements between a person with a learning disability who is growing older and, for example, their parents, will become increasingly common over time and it is welcome that NICE are recognising this in these guidelines.
41	Carers Trust	1	It is good to see NICE advising that professionals carrying out assessments of the needs of people with learning disabilities “may also need the support of family members or carers to ensure that the person has a true opportunity to express their needs, aspirations and desires”. This recognises that carers will have vital information about how the person with learning disabilities understands and communicates.
42	Down Syndrome Association	1	For individuals with a learning disability to be actively involved in the assessment of their care and support needs you will need staff who are well trained in communication skills and have a range of accessible information materials to help support them in their work.
43	Down Syndrome Association	1	Professionals will need to be allocated sufficient time in order to make this involvement meaningful and ensure that involvement is not cursory.
44	Down Syndrome Association	1	Involvement needs to begin early in order to prepare the individual sufficiently, especially when the individual may be transitioning from one life stage to another e.g. into adult services or when someone might be developing dementia in older age.

45	Foundation for People with Learning Disabilities	1	It is paramount that people are involved in all that effects their life. Planning should be ongoing and based on informed choice and the involvement of advocates or circle of support to ensure it reflects the way the person want to live. It is important to consider the needs of both the person with a learning disability and their ageing parents if they are living together. Mutual caring can support the way we think in that we plan for the life the person wants and put in place the things that are needed to make the transition to living when their parents are no longer alive easier. the operative word here is actively include to make informed decisions and choices. Changes and calling an assessment should be possible for both the system and the individual whose assessment it is. It should ensure that the assessment is based on the persons wishes and needs as close as possible and not based on the amount of resource available. Being creative in ensuring that the assessment can lead to change beyond the boundaries of resources. Preparation for the assessment should be initiated so that the individual is able to prepare for the assessment with those that know them best. Ensuring the assessment includes inclusion and community connecting to ensure the person leads a good life in the community and combat loneliness and isolation.
46	Local Government Association (LGA)	1	The rationale section (Page 4) says; 'That to enable people with a learning disability to be actively involved in the process, the practitioner carrying out the assessment will already have a good relationship with the person…' The LGA supports person centred care and actively involving people with a learning disability - but a practitioner with an existing good relationship with the person may not always be available because of capacity or resources. So it is important that the service has a good overall understanding of / and commitment to person centre care. The LGA and partners outline their vision for person centred care in the November 2018 report 'Shifting the Centre of Gravity'. The headlines from this report are: - Individuals using health and care services experience positive outcomes - Individuals, populations and communities maximise their health and wellbeing - Front line staff use their experience and expertise to shape seamless care - Leaders work effectively across health and care to drive transformation https://www.local.gov.uk/shifting-centre-gravity-making-place-based-person-centred-health-and-care-reality

47	Mencap	1	This item is clearly of the utmost importance, however, we feel this is vital for all people with a learning disability, and does not feel specific to older people. However, we do recognise its importance here, as it is an area where care can clearly improve – and will have a direct impact on the care of older people. This standard should make clear the importance of the availability of advocacy, which may take a more important role as people get older due to changes in their social and family circles. Good involvement in care planning must also take account of the importance of including those close to the person as they wish, and as dictated by the MCA.
48	Royal College of Psychiatrists	1	This needs to be measured both in primary care (annual health check) and secondary care including acute hospital admissions whether for physical health conditions or mental health and challenging behaviour. The use of patient passports (that incorporates views of the patient and family), completion rates and time to completion of decision support tools for health and social care needs of older individuals with LD to be met. These need to be measured to assess whether Person centred assessments are carried out in a timely and meaningful way with the views of the patient facilitated in the process using practicable means (SALT involvement). Recording of assessment of capacity and best interests for particular decisions also need to picked up.
49	Royal College of Speech and Language Therapists	1	To support a good quality assessment, people with communication difficulties must be referred to a speech and language therapist, when needed, to maximise their communication ability and support decision making.
50	Royal College of Speech and Language Therapists	1	We would support identifying more specific data source for evidence of active involvement in care and support assessment as active engagement is very dependent on communication skills of the assessor and the person being assessed, and this may require evidence from a speech and language therapy assessment.
51	Skills for Care	1	We would anticipate that all people with a learning disability would be ‘actively’ involved when their care is being discussed and have a plan for the future that is reviewed etc.

52	The Challenging Behaviour Foundation	1	This statement needs to include considering how people with severe learning disabilities and behaviour described as challenging will be actively involved in their care. Staff will need to use appropriate and effective communication skills to be able to meet individual's specific communication needs and involve them in their care. People who have a severe learning disability often do not communicate verbally, but may use other methods of communication, such as signing or using picture systems. Communication methods need to be unique and specific to each individual. This should include consideration of a person's behaviour. Challenging behaviour itself is often communication of an unmet need, so understanding the function of behaviour can help to improve the way a person's needs or wishes are understood. People will need appropriate training to ensure they have the necessary skills to achieve this and involve people with a learning disability actively in their care. There needs to be sufficient capacity and capability within the Social Care workforce. This issue is a finding of the 2017 National Audit Office report which concluded that there is a lack of a workforce with the right skills to support people with learning disabilities in the community. This statement should include the role of advocacy and that independent advocacy should be provided whenever it is needed or wanted by a person with learning disabilities'
53	Association of Directors of Adult Social Services	2	This standard appears to relate to a wider section of the community who may currently be in receipt of care and support from statutory services. It is unclear how under current funding constraints a lead practitioner could be provided for all people with learning disabilities meeting the definition within this standard by statutory agencies.
54	Association of Directors of Adult Social Services	2	Strong rationale but see comment above in terms of how achievable this objective is under current resource constraints
55	British Dental Association	2	The lead practitioner's responsibility should include dentistry and be aware that this group of patients are likely to access services via Community Dental Services (CDS). They may want to have formal links with the Special Care Dentistry MCN.
56	British Dental Association	2	If dentists are expected to work closely with the lead practitioner and other health and social care practitioners this would require far greater integration, both in terms of systems and IT, than is currently the case. Dentists, for example, do not have access to patients' summary care records, which would seem critical to fulfilling the close working set out in the standard.
57	British Dental Association	2	As above, there is a need for any information sharing to extend to the CDS and General Dental Service (GDS).

58	British Institute of Learning Disabilities (BILD)	2	Very supportive of role of lead practitioner but concerned about areas where this is not viewed as a priority
59	Camphill Families & Friends.	2	Some adults with a learning disability live in supported communities. Communities comprise not only formal communities of various types like Camphill but also informal communities, e.g. when people with learning disabilities share a life with one another as well as with supporters in shared or linked houses etc. In such cases there are often formed Circles of Support comprising friends, supporters (formal and informal), families and others (e.g. volunteers) who support and help in varying ways the lives of the learning disabled individuals, including decision-making. These Circles are extremely important to people with learning disabilities and play a large part in most aspects of their lives. They should be included in all planning and decision-making and mentioned as such. We recommend adding a specific acknowledgement that members of these communities – including staff – should therefore also have a named person who they can contact when they or the person with a learning disability they support need help or advice – alongside family members.
60	Carers Trust	2	Carers Trust welcome the inclusion of a named lead practitioner responsible for coordinating their care and support. One of the challenges carers face is the coordination of care, particularly between health and social care. Having a named lead coordinator will help both the person with learning disabilities growing older and their carers to access the help and support they need.
61	Carers Trust	2	Carers Trust are pleased to see NICE is recommending a “lead practitioner, who is the point of contact for people with a learning disability, their family members and carers, can support coordinating care between different health and social care providers as the person's needs change.” We also welcome the inclusion as part of their role ensuring that the needs of the carers are met across different services. We know that care coordination is one of the biggest challenges carers face. To have a single point of contact will be a good step forward to ensuring carers can get the support they need, whilst caring for the person with learning disabilities
62	Carers Trust	2	Carers Trust are encouraged to see that the views of carers will be taken into account when measuring the outcomes of the provision of coordinated care and support and the lead practitioner responsible for coordinating care.

63	Down Syndrome Association	2	We broadly support the introduction of a named lead practitioner, but we would support an individual's right to have a choice over who this individual might be, rather than the individual being imposed upon them.
64	Down Syndrome Association	2	Lead practitioners would need to have robust and comprehensive training programme to ensure they have the necessary skills and knowledge to perform this specialist role.
65	Down Syndrome Association	2	The roll out of a lead practitioner service would need to be all UK and not piecemeal according to local protocols, otherwise this would lead to a postcode lottery of provision.
66	Down Syndrome Association	2	Lead practitioners would need to have a range of nationally commissioned, quality assured, resources to support them in this new role.
67	Foundation for People with Learning Disabilities	2	A named practitioner that can act as navigator in the system and be the main point of contact is something families and individuals have asked for many times. However, it is important to review the relationship so that it is based on trust and respect. If the individual is unable to work with the named person then this should be changed without prejudice. There needs to be a point of complaint or seeking advise. The named person should be creative in finding the support required and should not always be in services. Mainstream may also provide creative solutions to peoples needs and inclusion, to avoid loneliness and isolation, should form part of planning. The named practitioner should be allocated at the point of referral and be able to navigate the person from childhood to adulthood and old age as far as possible. If the named practitioner leaves they should take time to introduce the new names person to the individual. This will avoid unnecessary misunderstandings and failures in support.
68	Mencap	2	We agree this is absolutely vital, but feel it is important to recognise there may need to be substantial changes to services – both across health and social care - and how they work together, in order to make this a reality: Clear guidelines will be invaluable to support understanding of what good co-ordination of care looks like. Again, this issue is important for all people with a learning disability, but is particularly important for older people who may experience changing needs and the complexity of those needs may increase. Other elements of these quality standards have a role to play in co-ordination of care, and should be linked in – including those related to annual health checks, and care planning, and hospital care.

69	NHS England	2	There should be a case coordinator, particularly for individuals living with two or more long term conditions. How will this group of people be visible on local commissioning dashboards, given the intention to use the current frailty index in a more proactive and preventative way. Important this is built into the development of Primary Care Networks too (JOH)
70	NHS England	2	Collating data for this quality standard may be challenging as those identified as a named lead practitioner may be from a wide range of health and care services. Collation of data to support this quality standard will be challenged where details are kept in paper form and where a number of electronic systems are used. (SC)
71	Royal College of Occupational Therapists	2	Lead practitioners working with people in community LD teams are also Occupational Therapists (not just nurses and social workers)
72	Royal College of Psychiatrists	2	In addition to what is mentioned in the document – assessment of CPA documentation, evidence from Care and Treatment Reviews for older adults with LD in the community as well as inpatient Learning Disability units (assessment and treatment units, secure units).
73	The Challenging Behaviour Foundation	2	The named lead practitioner needs to be competent with an appropriate level of skills, knowledge and experience to coordinate care and support for people with learning disabilities. There is not currently an adequate skilled workforce. This is evidenced in the 2018 HEE draft health and care workforce strategy 'Facing The Facts, Shaping The Future' which noted that while numbers of staff in the NHS are increasing on the whole, numbers of Learning Disability nurses are decreasing- there are 842 fewer LD nurses (36.5% decrease) than in 2012.
74	Association of Directors of Adult Social Services	3	As with previous standard, this implies a wider "universal" coverage for people with learning disabilities. Only those people with learning disabilities with identified eligible care and support needs are likely to have a
75	Association of Directors of Adult Social Services	3	Whilst it is accepted that a specific age limit would be problematic as aging can be experienced earlier than in the general population, there needs to be consideration of some form of "triggers" for professional to be considering age related issues - particularly for those who do not have a care and support plan and are therefore unlikely to have a designated "lead practitioner" (e.g. the 75+ health check for older people was a universal trigger)
76	British Dental Association	3	Annual reviews should consider oral health needs. For continuity of care, it is advisable for patients to see the same dental team in the long-term.

77	British Institute of Learning Disabilities (BILD)	3	Need for increased knowledge for individuals with learning disability and family carers need to identify what specific support will be needed to help individuals, family, friends, peers to understand the changes that they are experiencing
78	British Institute of Learning Disabilities (BILD)	3	Needs are flexibly met in ways that make sense to each individual as opposed to being service led. Appropriate learning and development opportunities for frontline workers.
79	British Institute of Learning Disabilities (BILD)	3	Environmental changes to be considered, not just leaving current home
80	British Institute of Learning Disabilities (BILD)	3	Emphasis on ensuring that high quality of end of life care is provided
81	Camphill Families & Friends.	3	Some adults with a learning disability live in supported communities. Communities comprise not only formal communities of various types like Camphill but also informal communities, e.g. when people with learning disabilities share a life with one another as well as with supporters in shared or linked houses etc. In such cases there are often formed Circles of Support comprising friends, supporters (formal and informal), families and others (e.g. volunteers) who support and help in varying ways the lives of the learning disabled individuals, including decision-making. These Circles are extremely important to people with learning disabilities and play a large part in most aspects of their lives. They should be included in all planning and decision-making and mentioned as such. We recommend adding a specific acknowledgement that members of these communities – including staff – should therefore also be involved in making plans for the future with the person with a learning disability as they grow older. Their caring responsibilities should be recognised in these plans as well – alongside family members.

82	Carers Trust	3	As with Statement 1, which sets out the need to include unpaid carers in the care planning of the person with learning disabilities. It is important that carers are involved in future planning and review. As the person with learning disabilities is getting older, their carers – often parents – will also be getting older and will need to know that care of their child or children with learning disabilities is secure, when they are unable to continue in their caring role. The inclusion of carers in the rationale would better align this Quality Statement with The Structure of the Quality Statement, which sets out the need to "work with family members and carers…to agree on plans for the future." It would also better align with the "What the quality statement means for different audiences" section of the Quality Statement which sets out the expectations that "family members and carers are involved in making plans for the future with the person with a learning disability as they grow older.
83	Down Syndrome Association	3	Any plan that is developed should be truly person-centred and make available appropriate levels of funding to meet the individuals needs
84	Foundation for People with Learning Disabilities	3	The plan should consider mutual caring and continuing this is it is the persons choice. Whilst planning for the future and when the parent is no longer there. planning to focus on dreams and wishes so that it captures if the person is no longer able to make decisions. They should be able to allocate named person from their circle that can protect their dreams and wishes. Planning to consider the way to lead and inclusive lifestyle and find solutions in mainstream and community. Not just specialist services.

85	Mencap	3	We agree this is really important – but recognise this is important for everyone – not just older people, particularly those approaching any kind of transition point. Planning is particularly important for older people who have specific needs – and whose needs are likely to change – we feel it is important that this quality standard makes clear that people must be involved in planning throughout their lives, and it must not be left until a person starts to lose ability, or capacity. Planning must also take account of how any signs of deterioration will be picked up and should make use of baselines to track this. In addition, sensitive planning around end of life care is important for older people. With all this in mind, we would like to see this outcome made more specific for older people with a learning disability. In addition to the items named above, it must also must include social inclusion as well as health and care needs, including making new friends, and trying new things – which can be just as important as maintaining old interests and friendships. It must also take into account the role that some older people with a learning disability may have taken on a caring role due to changing family relationships at this time. This outcome should also include all of the points we have set out in the section above relating to involvement of people with a learning disability in care planning.
86	NHS England	3	Important to be included in current and future digital technology/innovations to help keep people safe in their community QOF and local audits/quality improvement work important (JOH)
87	Patient and Client Council	3	The Patient and Client Council has worked closely with Carers of people with a learning disability in recent years around the subject of future planning. Specifically for a time when carers/family/loved ones are unable to provide care. If this work can be of assistance I would be happy share findings. A training package has also been developed to support carers to plan ahead.
88	Royal College of Nursing	3	Standard 3 should also include sexual health needs in the descriptors.
89	Royal College of Occupational Therapists	3	The Healthcare practitioner for the Annual Health Care checks can also be an Occupational Therapist (not just nurses or GPs)
90	Royal College of Psychiatrists	3	As in 1 and 2 above.

91	The Challenging Behaviour Foundation	3	When planning for the future it needs to be acknowledged that there is evidence to suggest the care of people with severe learning disabilities and behaviours that challenge is currently inadequate. Individuals with learning disabilities and behaviour perceived as challenging are likely to: • Live in places or with people they don't like, often a long way from their family home. • Be given too much medication, or inappropriate medication. • Be subjected to restraint. • Be secluded and have their movement restricted. Many people with a learning disability have ended up in an inpatient unit due to a failure to provide or develop the right support and services in the local community. At the end of January there were 2,305 people with a learning disability and/ or autism in inpatient services. In October 2015, 'Building the Right Support' aimed to close 35-50% of in-patient beds and ensure the right community support was developed by March 2019. However, there is universal agreement that this has not been achieved. The NHS Long Term plan extends the targets of a 35-50% reduction to 2023/24 accepting failure to meet the target by the end of March 2019 (NHS Long Term Plan, January 2019). To plan for the future and ensure the right community support for people with learning disabilities there are issues, highlighted in the recommendations from the evaluation of Building the Right support (2018) including commissioning, workforce and housing which need to be addressed.
92	Association for Family Therapy and Systemic Practice - UK	4	When considering support for people to improve their health it may be important to acknowledge that when considering weight issues, the support of informal (or often formal) carers can be based on popular dieting models which are not effective and which can sometimes be extremely counter-productive because they can result in states of deprivation and inadequate management of hunger which leads to rebound overeating. We think that the people supporting the person living with learning disabilities should be given accurate information from a dietitian or NHS nutrition assistant in order to support sustainable changes.
93	Association of Directors of Adult Social Services	4	This relies on the extent to which GP practices engage with the NHS LD Health Check Scheme. The scheme is voluntary and only undertaken as part of Enhanced GP services.
94	British Dental Association	4	The health action plan needs to consider dentistry and oral health needs.

95	British Dental Association	4	It should be noted that this check does not include a review of oral health. Maintaining oral health is important not only in and of itself, but because of the links between oral health status and general health.
96	British Institute of Learning Disabilities (BILD)	4	More emphasis needed on issues of dementia; also better pain management and ability to prolong life in quality ways and reducing the risk of premature death
97	Camphill Families & Friends.	4	Some adults with a learning disability live in supported communities. Communities comprise not only formal communities of various types like Camphill but also informal communities, e.g. when people with learning disabilities share a life with one another as well as with supporters in shared or linked houses etc. In such cases there are often formed Circles of Support comprising friends, supporters (formal and informal), families and others (e.g. volunteers) who support and help in varying ways the lives of the learning disabled individuals, including decision-making. These Circles are extremely important to people with learning disabilities and play a large part in most aspects of their lives. They should be included in all planning and decision-making and mentioned as such. We recommend adding a specific acknowledgement that members of these communities – including staff –should therefore also be involved in the annual health check for the person with a learning disability. They can raise any concerns about the health of the person and help the health professionals see the person and not just their disability. They can also find out how to support the person to stay healthy and look after themselves as they grow older -– alongside family members.
98	Carers Trust	4	We are pleased to see that “a review of family carer needs” is included as part of the minimum required protocol for this annual health check. As with elsewhere in the guidelines, NICE should set out that carers are not always family members.
99	Down Syndrome Association	4	We note that there is currently widespread variance in uptake and quality of Annual Health Checks. Health Action Plans can only be as good as the health check upon which they are based. This should be an area targeted for significant improvement, given the wide ranging health inequalities experienced by many adults with a learning disability.

100	Down Syndrome Association	4	We would draw attention to the specific health needs of adults with Down's syndrome and reference the work of the Down's Syndrome Medical Interest Group www.dsmig.org.uk on specific areas of health including growth, cardiac issues, thyroid disorder, sensory issues etc. There is also a comprehensive range of resources for family carers on The Down's Syndrome Association's website https://www.downs-syndrome.org.uk/for-families-and-carers/health-and-well-being/health-series/?highlight=medical%20series
101	Down Syndrome Association	4	There is a significant need for health improvement outcomes for adults with a learning disability, as demonstrated by some of the early findings reported by the LeDeR programme, where many adults with Down's syndrome have been involved in some of the most worrying cases.
102	Down Syndrome Association	4	The incidence of dementia amongst adults with a learning disability (especially adults with Down's syndrome) is significantly higher and age of onset is much younger. We would reference the work of Dr Andre Strydom and the London Down Syndrome Consortium https://www.ucl.ac.uk/london-down-syndrome-consortium/ in helping understand the specific health needs of this population and the need for nationally agreed monitoring protocols to assist with the early identification of dementia in this group of people.
103	Foundation for People with Learning Disabilities	4	Remembering to include mental health and wellbeing within the health check. With community prescribing to ensure the person can stay healthy. Social prescribing to be allocated to the individual and not to services. The person should then be able to spend it on the named items. Eg. Paying for a gym instead of the money allocated to a service as a pot which precludes people to have any control. Use the Feeling Down Guide which can be found on the FPLD web site, to assist with keeping a record of people mental health as evidence for the GP to be added to the health action plan.
104	Manchester Metropilitan University	4	The focus in the standard seems to be very much on physical health and health services. What about social issues like social isolation? People with learning disabilities are more likely to become socially isolated as they grow older (e.g. if their health deteriorates, their family and friends die, their support changes). This can impact on their health and wellbeing. Will plans and lead practitioners look at whether someone is socially isolated and what can be done about this? We are doing an inclusive research project GM GOLD about how to reduce social isolation amongst older people with learning disabilities in Greater Manchester (@wearegmgold).

105	Mencap	4	We were not sure that the health action plan itself was the correct thing to focus on here. Instead, we recommend rather to concentrate on the quality of the health check itself and how it is used to address the specific needs of older people. A good health action plan is of course a marker of a good quality health check. The GP can be one of the most consistent roles in people's care – and in our experience as regards providing care and support services, people may see their GP very often. However, we have also encountered barriers to accessing annual health checks, particularly where a GP may not immediately understand the importance of having a health check if they have already seen someone recently. If this standard relates to the GP following the NHS England template (which is currently optional), then we could mandate that particular sections of the health check are given full attention for older people, including baseline readings, dementia assessment, behaviour changes, end of life care (where appropriate), co-ordination of care – and involvement of care co-ordinator, and ensuring SCR additional information and any local flagging mechanisms are up to date, and that patients have a health action plan which reflects all this.
106	NHS England	4	Annual health checks are not mandated but an enhanced service based on QOF registers. Access to memory services patchy as in practice this provision often falls within Community Teams for People with Learning Disabilities (CTLDs) and they do not get access to services used by their non-learning-disabled peers. Mental Health screening is already included in Annual Health Checks offered to people with learning disabilities identified on the GP register. Would be important to include memory assessments, particularly for older people with learning disabilities and those more at risk e.g. people with Down Syndrome. People with learning disabilities age earlier than the general population, and experience age-related health conditions earlier than their peers. Can this guidance be worded to take this into account, so growing older rather than 65+ years? (JOH)
107	Patient and Client Council	4	I would be grateful if you would consider the report linked: http://www.patientclientcouncil.hscni.net/uploads/research/1748_LFA40w.pdf . This is a recent service evaluation on Annual health checks for people with a learning disability. People interviewed in this worked also spoke on their experience of secondary care services
108	Royal College of Psychiatrists	4	Happy with what is covered in the document

109	Royal College of Speech and Language Therapists	4	The annual health check will include a review of physical health including dysphagia. We would suggest this needs to be discussed in an accessible manner and include a discussion of - Any changes to eating, drinking or swallowing ability - Any coughing or choking when eating, drinking or swallowing - Enjoyment and preferences related to any eating, drinking or swallowing difficulties.
110	Royal College of Speech and Language Therapists	4	The QS mentions that the Annual Health Check will cover a review of communication needs. We would suggest that this should cover the following: - A discussion of any changes in communication ability - refer people with communication difficulties to speech and language therapy - Situational changes altering need for communication support, for example interview preparation or making a speech.
111	The Challenging Behaviour Foundation	4	There are two major challenges that impact on healthcare for people who have a severe learning disability and display behaviours described as challenging. Firstly, accessing health care and secondly, the quality of the service they receive. Making reasonable adjustments for the individual can enable access to health services. This statement needs to include that in line with the Equality Act 2010, people with a severe learning disability should be given reasonable adjustments when accessing health care. Within this statement around the health needs of people with learning disabilities it is important to acknowledge the need to regularly review medication a person with learning disability is taking and consider alternative treatment options. Many people with severe learning disabilities are prescribed too much and/or inappropriate medication. This has been recognised by NHS England's STOMP programme, and a suite of research, such as Public Health England's research into the use of psychotropic drugs with people who have a learning disability . Any person with a severe learning disability who is prescribed medication should have this medication reviewed regularly to monitor effectiveness, identify side effects and consider whether a less restrictive alternative / lower dose could be used.
112	Association of Directors of Adult Social Services	5	This standard only relates to "Planned" admissions - the case for extending this standard to "ALL" acute admissions is strong. Access to a designated LD Liaison Nurse, in the same way as Psychiatric Liaison is now commonplace in A&E for people with mental health conditions, would be a reasonable standard to apply.

113	Association of Directors of Adult Social Services	5	The standard could also be extended to cover Hospital Discharge. This would be a useful tool in ensuring that someone admitted who perhaps was not receiving care and support previously would have any new factors - including issues relating to age related conditions recognised and appropriate support levels reviewed.
114	British Dental Association	5	This pre-admission meeting should consider how patients' oral health and hygiene needs will be met during hospitalisation. There is a proven link between hospitalisation and deterioration in oral hygiene, which can lead to a wide range of health problems including under- and mal-nutrition, dysphagia, and in some cases hospital/incubator-acquired pneumonia.
115	British Institute of Learning Disabilities (BILD)	5	Stronger emphasis on addressing the communication requirements of each individual and who would be best place to address this.
116	Camphill Families & Friends.	5	We recommend removing the phrase 'if that is the wish of the person with a learning disability' from this section. This would be in line with the wording of Quality Statements 1,2,3 and 4, where a family member/carer is able to get involved without the need for this to be expressed as the wish of the person with the learning disability. Sometimes a person with learning disabilities may not understand the extent to which having a someone present is useful, and may therefore end up in a meeting where they aren't able to explain their needs properly.
117	Camphill Families & Friends.	5	Some adults with a learning disability live in supported communities. Communities comprise not only formal communities of various types like Camphill but also informal communities, e.g. when people with learning disabilities share a life with one another as well as with supporters in shared or linked houses etc. In such cases there are often formed Circles of Support comprising friends, supporters (formal and informal), families and others (e.g. volunteers) who support and help in varying ways the lives of the learning disabled individuals, including decision-making. These Circles are extremely important to people with learning disabilities and play a large part in most aspects of their lives. They should be included in all planning and decision-making and mentioned as such. We recommend adding a specific acknowledgement that members of these communities – including staff – therefore should take part in a planning meeting with hospital staff before the person with a learning disability goes into, with the option of a family member, carer or community member staying overnight in the hospital.
118	Carers Trust	5	Carers trust welcome that NICE has set out the need to include carers in pre-admission meetings with the hospital liaison team. It is also good to see that service providers will be experienced to have arrangements in place for carers to stay overnight.

119	Down Syndrome Association	5	We welcome planning to enable hospitals to make reasonable adjustments for people with learning disability who have a planned hospital admission, however, it is only a proportion of hospital stays which are planned. Many admissions will be as the result of a medical emergency and it is imperative that acute settings also have the facility to meet the needs of patients with a learning disability and assess their needs and make reasonable adjustments quickly.
120	Foundation for People with Learning Disabilities	5	A hospital passport can be developed to ensure everyone knows how to communicate with the individual and their dos and don'ts. To include any support needs for example completing food request for day.
121	Mencap	5	We agree these are important, and can really help a hospital admission to be a success, but felt this is not an item that is relevant to older people specifically: we think this is important for ALL people with a learning disability. To meet the specific needs of older people, we want to see this item expanded to include improvements to discharge procedures – including a good understanding of how different types of support work – difference between care homes, supported living – and how services can adapt. We also want to see more to improve emergency admissions – where there is more possibility the person may be alone without support – this of course goes hand in hand with the improved health checks and care co-ordination
122	NHS England	5	NHSI Learning Disability Standards as above Planned Digital Flag for reasonable adjustments for people with learning disabilities is an objective within the NHS Long Term Plan (JOH)
123	Patient and Client Council	5	I would be grateful if you would consider the report linked: http://www.patientclientcouncil.hscni.net/uploads/research/1748_LFA40w.pdf . This is a recent service evaluation on Annual health checks for people with a learning disability. People interviewed in this worked also spoke on their experience of secondary care services
124	Royal College of General Practitioners	5	This needs to be resourced in each hospital so that staff are available to liaise and help ensure older adults with a learning disability are looked after in hospitals and to avoid revolved doors
125	Royal College of Psychiatrists	5	It would be important to check for local information whether or not there is adequate staff availability and provision of both general nursing trained and learning disability nursing trained for planned admissions for routine operations, investigations or treatment in acute hospitals, for supporting older adults with learning disability. This would need to be incorporated in the quality standard to ensure the right support and care is readily available to older patients with learning disability.

126	The Challenging Behaviour Foundation	5	A statement on hospital admissions needs to include standards around unplanned hospital admissions and the importance of early intervention and prevention support in the community to prevent unnecessary hospital admissions.
127	Mencap	Additional areas	Training for staff is not included in current recommendations, however we strongly recommend that it is. Staff should be trained according to the updated Learning disability core skills framework –which includes a section on the needs of older people – at the tier appropriate to their role. It is vital that the health and social care team surrounding an older person with a learning disability are able to identify and support health conditions that may deteriorate rapidly, including urine infections, dementia, incontinence and skin conditions – as well as supporting people with increasing mobility needs. They must also be aware of how to respond to changing abilities – such as frailty or cognitive decline. Staff must be aware of how to seek involvement from occupation health – to help them use new equipment, and gain an understanding of what kinds of equipment may be available. End of life care training is also necessary, this needs to include very practical issues, such as how to prevent bed sores and dealing with deterioration in swallowing – but also of course the emotional support they will need to provide – and will need themselves. We also believe training may also help social and health care staff to involve families and loved ones at this time
128	Mencap	Additional areas	Dementia care – We believe this is very important and must be addressed within these standards, as dementia affects such a high number of people with a learning disability - and much improvement is needed in practice in this area. Good planning, record keeping, use of baselines and annual health checks can help spot the signs earlier. Good forward planning, responsive and co-ordinated care can help as dementia progresses. Specific points relevant to dementia care and assessment could be included within all the elements we have recommended so far, and we recommend that it is. We have raised concerns in the recent past that the existing NICE guidance for dementia is not of a sufficient standard to ensure good care for people with a learning disability at risk of or experiencing dementia. We recommend that in order to improve care in this area, that this guidance itself is revised. Mencap would be very pleased to assist with this work.

129	The Challenging Behaviour Foundation	Additional areas	Safeguarding is an important issue that needs to be included within these statements. People with learning disabilities are at risk of abuse. It is important that robust systems are in place to prevent and identify abuse of this group, with all areas working effectively, in coordination and communicating effectively to prevent abuse being missed. There is much evidence demonstrating how people with learning disabilities have a poor experience of safeguarding. Panorama revealed shocking abuse of people with learning disability at Winterbourne View Hospital in 2011. Since then safeguarding has continued to fail people with a learning disability. People with a learning disability are sectioned inappropriately, spending many years in units, experiencing abuse and neglect, including overuse of restrictive practices, not receiving any proper 'assessment or treatment' and not being able to get out and live a fulfilling life, with the right support in their local community. Evidence of this can be found in Mencap and the Challenging Behaviour Foundations 'Out of Sight' report, the report 'Winterbourne View: the Scandal Continues', and the Care Quality Commission and Challenging Behaviour Foundation's 'Three Lives' report secure hospitals.

Registered stakeholders who submitted comments at consultation

- Association for Family Therapy and Systemic Practice - UK
- Association of Directors of Adult Social Services
- British Dental Association
- British Institute of Learning Disabilities (BILD)
- Camphill Families & Friends.
- Carers Trust
- Dimensions

- Down Syndrome Association
- Family Planning Association
- Foundation for People with Learning Disabilities
- Local Government Association (LGA)
- Manchester Metropolitan University
- Mencap
- NHS England
- Patient and Client Council
- Royal College of General Practitioners
- Royal College of Nursing
- Royal College of Occupational Therapists
- Royal College of Psychiatrists
- Royal College of Speech and Language Therapists
- Skills for Care
- The Challenging Behaviour Foundation
- The Dirac Foundation