Care and support of people growing older with learning disabilities

Consultation on draft guideline - Stakeholder comments table
03/11/2017 to 15/12/2017

Stakeholder	Document	Page No	Line No	Comments	Developer's response
Affinity Trust	Full	General	general	There should be more reference to supporting older people who are experiencing bereavement, either of family or their peers as this can have an adverse effect on mental wellbeing. Greater reference to informal carers Health Action Plans need to be emphasised as they are the main way in which professionals can plan together to support people who may have complex health needs. Many older people with learning disabilities will have fluctuating capacity and this may be something staff have not seen before so they will need support and training to understand and manage this.	Thank you for your comment. Recommendation 1.4.4 refers to support for people following a bereavement. We do not use the term informal carers in the guideline, but instead refer to family members, carers and advocates. We recognise their importance and they are covered extensively. Recommendation 1.1.8 makes clear that must understand and consider the Mental Capacity Act 2005 when working with older people with learning disabilities. Following stakeholder comments, we have also added reference to the Mental Capacity Act to recommendation 1.7.3 on training. There is an additional NICE guideline in development on Decision making and mental capacity.
Age UK	Full	General	General	Question 1: The guidance should make clear that care settings for older adults with learning disabilities should always be age-appropriate. Individuals should not be expected or required to move from their own home to a residential care setting unless it is appropriate for their needs and age.	Thank you for your comment. This issue is reflected in recommendation 1.2.4, which states that commissioners and providers should provide housing options that meet the changing needs of people with learning disabilities as they grow older.
Age UK	Full	General	General	Question 2: As previous NHS England commissioning and NICE cost saving guidance makes clear, reducing incidences of malnutrition are estimated to have the third highest potential to deliver cost savings to the NHS.	Thank you for your comment. Malnutrition has been added to the list of conditions which people and their families should be trained to recognise and manage (recommendation 1.5.6), and which healthcare professionals should monitor for (recommendation 1.5.13).
Age UK	Full	General	General	Question 3: Use of existing NICE guidelines on malnutrition and use of checklists such as the Malnutrition Universal Screening Tool (MUST) can assist health and care professionals to identify and support those at risk or suffering from malnutrition.	Thank you for your comment .We did not find evidence in relation to the Malnutrition Universal Screening Tool (MUST), so are unable to recommend it here. However we have now added to Recommendation 1.5.6 this statement: 'For further guidance on nutritional support see NICE guidelines on malnutrition.
Age UK	Short	16	18	The list of age-related conditions which individuals, their family members and carers should consider training to recognise and manage should include those at risk of and suffering from malnutrition.	Thank you for your comment. The committee considered you point and felt it was clearer to simply say 'malnutrition', which would cover risks of and signs of malnutrition.
Age UK	Short	17	28	Risk of and actual malnutrition should be included as an age-related condition that is discussed and which people are monitored for symptoms of.	Thank you for your comment. We have amended the recommendation adding 'malnutrition' to the list of conditions.
Alzheimer's Society	Short	22-23	16-6	Alzheimer's Society supports the provision to improve awareness and understanding about the link between learning disabilities and dementia. People with learning disabilities are at increased risk of dementia. People with learning disabilities will face some differences in the way they experience dementia, including experiencing a more rapid progression of dementia. Moreover, they may already be receiving social care prior to their diagnosis of dementia, and may need specific support to understand the changes they are experiencing.	Thank you for your support and the additional information. The committee discussed the genetic link between learning disabilities and dementia and were glad to have evidence from the systematic review on which to develop specific recommendations about the identification, management and provision of support for people with learning disabilities and dementia.

				Alzheimer's Society research has found that people with learning disabilities who have dementia have difficulties in getting a diagnosis, which is why the organisation welcomes the proposal to encourage awareness for families about the symptoms and early signs of dementia in people with learning disabilities. Given the particular difficulties people with learning disabilities and dementia may face, the organisation also supports the recommendation to provide carers and family members, as well as the people affected, with advice on communication strategies. This also applies to the recommendation for commissioners to provide specific information to people with learning disabilities who are in the process of being diagnosed to ensure they have the support they need in a timely manager. Finally, Alzheimer's Society welcomes the recommendation to consider specific training for assessors and care workers the needs of people with learning disabilities and dementia, to guarantee that they are able to provide person-centred care that takes into account peoples' specific needs. We know that in general, there is a lack of training for people providing care and support to people with dementia, and given the complex symptoms associated with dementia and learning disabilities, specific provision of training alongside wider dementia training would be beneficial to people affected.	
Alzheimer's Society	Short	6	19-22	Alzheimer's Society supports the recommendation to ensure practitioners support people's communication preferences in line with NHS England's Accessible Information Standard. One of the symptoms of dementia is difficulty in communicating, which can impact peoples' ability to engage with and access information. If someone has a learning disability and is affected by dementia, difficulties with communication may be greater, and must reflect an individual's specific needs and preferences. As such, recommendations to offer visual aids, extending appointments and involving the person in making decisions about what kind of communication they prefer is very much welcomed on the part of the organisation. It is very important that the person is consulted about what communication styles are most suited to them, in order to enable person-centred care to be provided.	Thank you for your support and the information provided.
Alzheimer's Society	Short	7	10-17	From calls to Alzheimer's Society's helpline and in consultations with people affected by dementia, it has become clear that older people, people with dementia and people with learning disabilities are navigating a complex and disjointed health and care system. On average, Alzheimer's Society's research has found that people with dementia come into contact with 23 different bodies, organisations and professions over the course of their dementia journey and this can be both confusing and disorientating to someone. If they have dementia and a learning disability, this confusing web of care may be further exacerbated, especially given the heightened struggles in terms of communicating and engaging with information. As such, it is particularly important that people living with learning disabilities and dementia are provided with accessible information tailored to their needs about the care and support available to them. In addition, Alzheimer's Society supports the specific recommendation around providing information about housing options available to people	Thank you for your comment, which the committee have taken on board in finalising the guideline. They agreed to edit recommendation 1.1.6 to read, 'Provide people with…accessible, **tailored** information about…'

				affected, in order to help promote their independence and enable people to stay at home as long as possible (which our evidence shows is overwhelmingly peoples' preference.	
Alzheimer's Society	Short	23	7-11	Alzheimer's Society supports the recommendation to give older people with learning disabilities and carers accessible information about all care options available for end of life care, including services. Importantly, the access to such support must be timely and provided early after diagnosis, given the progressive nature of dementia – which affects peoples' capacity.	Thank you for your comment. This has been addressed in two ways; by adding 'timely' to recommendation 1.6.1 and by adding 'planning for end of life care' to the list of accessible, tailored information that should be provided to older people with learning disabilities and their families.
British Geriatrics Society, endorsed by the Royal College of Physicians	Full	General	General	Although the term 'Learning Disability' was introduced into official UK government communications in the 1990s, and used in the 2001 White Paper "Valuing People: a new strategy for learning disability for the 21st century", the UK is the only English-speaking country using this term and more recent NHS publications (e.g. "Raising Our Sights: services for adults with profound intellectual and multiple disabilities (2010)") have moved to the current internationally accepted terminology of "Intellectual Disability". This is the term now commonly used in research. "Learning Disability" is easily confused with "Learning Difficulty" in public perceptions. For these reasons, we suggest that NICE use the term "Intellectual Disability" throughout.	Thank you for your comment. The Guideline Committee considered this feedback, but decided to retain the term 'learning disability' for consistency with current policy from the Department of Health and Social care and NHS England (for example, in relation to Transforming Care).
British Geriatrics Society, endorsed by the Royal College of Physicians	Full		5519, 5777, 5905	Reference Fender A, Marsden L, John MS (2007) is incorrectly cited: it should be Fender A, Marsden L, Starr JM (2007). Such mis-citation does not inspire confidence in the attention to detail undertaken during the review process. We have not gone through the references exhaustively, but suggest that this is done before a final version is published.	Thank you for bringing this to our attention. This is an error due to how the reference was generated in the reference management software we used. This has now been rectified.
British Geriatrics Society, endorsed by the Royal College of Physicians	Full	General	general	Scope of literature search. Important evidence has been omitted; it is unclear why this was not identified. For example, Professor Nick Lennox developed the Comprehensive Health Assessment Program (CHAP) in Queensland, Australia which is now used widely. It is based on a randomised clinical trial: Lennox N, Bain C, Rey-Conde T, Purdie D, Bush R, Pandeya N. Effects of a comprehensive health assessment programme for Australian adults with intellectual disability: a cluster randomized trial. Int J Epidemiol. 2007 Feb;36(1):139-46. Lennox N, Bain C, Rey-Conde T, Taylor M, Boyle FM, Purdie DM, et al. Cluster randomized-controlled trial of interventions to improve health for adults with intellectual disability who live in private dwellings Journal of Applied Research in Intellectual Disabilities. 2010;23(4):303-11. As in point 2, this does not inspire confidence in the evidence upon which the drafts are based. It is particularly worrying given that this area has a paucity of RCT evidence. We suggest a thorough, robust literature search is undertaken. It might also be useful to contact health providers outside of the UK to elucidate what other health assessment approaches are implemented and the evidence on which these are based.	Thank you for highlighting these. Both these studies were located by our search but excluded on population at the first stage of screening on title and abstract due to the focus on adults rather than 'older people'. As for contacting health providers, this is not something the committee felt would have provided useful additional data. Although there was a paucity of evidence in some areas of the scope, the committee addressed those gaps though inviting expert witnesses to provide testimony as well as through their own expertise and experience.

British Geriatrics Society, endorsed by the Royal College of Physicians	Full	General	general	In general, the health sections are written from a 'service delivery' perspective. This is inappropriate given the desired aim of providing person-centred care. One study is cited in which older adults with intellectual disability in the UK were asked their views as to what constituted health: Fender A, Marsden L, Starr JM. Assessing the health of older adults with intellectual disabilities: a user-led approach. Journal of Intellectual Disabilities 2007;11:223-239. But this was subsequently developed into a practical assessment, informed by the CHAP (see point 3), implemented and related back to more conventional health metrics: Fender A, Marsden L, Starr JM. Assessing the health of older adults with intellectual disabilities: a user-led approach. Journal of Intellectual Disabilities 2007;11:223-239. Starr JM, Marsden L. Characterisation of User-defined Health Status in Older Adults with Intellectual Disabilities. Journal of Intellectual Disability Research 2008;52:483-489. This formed the basis of the standard recommendations in a leading textbook of Geriatric Medicine: Starr JM. The Older Adult with Intellectual Disability. In: Brocklehurst's Textbook of Geriatrics and Clinical Gerontology, 7th edition. Rockwood K (ed). Philadelphia, PA: Elsevier, 2010. (updated version in press for the 8th edition). Given that this user-informed health assessment, developed for UK populations of older adults with intellectual disability, captures aspects of health directly relevant to people with intellectual disability (rather than service providers) yet correlates well with standard health metrics such as disease burden, we suggest a refocussing of the guidance to take into account far more the views of people with intellectual disabilities which is the recommended approach for UK geriatricians.	Thank you for your comment. The evidence review which underpins the guideline included evidence on the views and experiences of people with learning disabilities. In the guideline, we have stressed the importance of providing person-centred care, in sections 1.1 (Overarching principles) and 1.4 (Planning and reviewing care and support).The recommendations are aimed at practitioners who should be providing care and support for older people with intellectual disabilities under the overarching principle of 'person-centred' care.
British Geriatrics Society, endorsed by the Royal College of Physicians	Full	General	General	Questions 1, 2 and 3. At this stage, given the major deficiencies in the draft guidelines as they stand, it is impossible to comment on the specific questions raised. We would be happy to do so once a new draft is available with the deficiencies highlighted above duly addressed.	Thank you for your comment. Having responded to yours and all other stakeholder comments and worked with the committee on a final revision of the guideline we trust that any perceived shortcomings have been addressed. The final version of the guideline will be published in April 2018.
British Psychological Society	Short	General	General	The Society welcomes this specific guideline for the care and support of older people with learning disabilities. However, we would recommend the term 'intellectual disabilities', in order to be consistent with the NICE guideline. However, the term 'learning disabilities' is used in the response below. We believe that full implementation of this guidance across health and social care services would significantly improve outcomes for people with learning disabilities. However, we do have some comments that we believe would enhance the guidance, which we have outlined in this consultation response.	Thank you for your comment. The Guideline Committee considered this feedback, but decided to retain the term 'learning disability' for consistency with current policy from the Department of Health and Social Care and NHS England (for example, in relation to Transforming Care).

British Psychological Society	Short	General	General	The Society has concerns regarding the lack of places for adults with learning disabilities and dementia in respite and residential facilities where staff had the right skills. We acknowledge that this guidance stresses the importance of staff training and working together, however we believe that the immediate need for training and for appropriate placements could be stressed further.	Thank you for your comment. On the basis of the evidence and their own expertise, the GC agreed with this point and more generally the lack of appropriate service provision for this population – they feel these issues have been adequately addressed in the recommendations, with specific sections dedicated to training and planning and commissioning local services.
British Psychological Society	Short	General	General	The Society believes that a core area for older people with learning disabilities is dementia, and that this requires specific considerations. We believe that recognition of the specific expertise required to assess dementia in people with learning disabilities, particularly given the challenges of this in people with learning disabilities who already have pre-existing impairments in cognitive and functional abilities, is paramount to good care pathways. This would be strengthened by the specific guidance in this area produced on *Dementia and People with Intellectual Disabilities*. (BPS, 2015).	Thank you for your comment. The guideline includes a section on care and support of people living with dementia, as well as highlighting the need to develop protocols for dementia support (recommendation 1.2.8), in ongoing monitoring (recommendation 1.5.13) and in relation to awareness amongst the workforce (recommendation 1.7.3).
British Psychological Society	Short	3	16-17	The Society believes that people with Down's syndrome also have an earlier age-related risk of developing dementia of the Alzheimers type (BPS, 2015) and that this should be further considered. Consider adding 'For example, there is a high prevalence of dementia in people with Down's Syndrome'… …'and people with Downs syndrome have an earlier age related risk of developing Alzheimer's type dementia.'	Thank you for your comment. The Committee acknowledged the high prevalence of dementia in people with Down's Syndrome in the context section (p3). The need for explanation, information giving and providing support relating to Down's Syndrome and dementia was addressed in recommendation1.5.36.
British Psychological Society	Short	3	19	The Society believes that the following should also be considered…. 'In particular, dementia presents differently in those with learning disabilities versus the general population, for example evidence strongly indicates that a frontal/behavioural presentation precedes anomia, and that pseudo dementia can be more prevalent, and can last significantly longer with no recovery in this population that the general population. (Ball, S.L., et al, 2006; BPS, 2015; BPS, 2014; Worley, G et al, 2014).	Thank you for your comment. This guideline is focused on care and support for people with learning disabilities as they grow older. Factors to consider in the diagnosis of particular conditions is outside the scope of the guideline.
British Psychological Society	Short	3	20	The Society welcomes the weight given to issues of poorer access to health care and higher mortality rates. However, it was noted that the guidance point: people with learning disabilities "may have increased risk of mortality due to conditions associated with their learning disability (for example epilepsy and aspiration pneumonia)" may be misleading as people with learning disabilities are most likely to die due to similar health problems for the general population. The causes of premature mortality are more likely to be due to poor healthcare which is noted later in this paragraph. We believe that this should be reworded the paragraph to reflect this. (Tyrer, F., 2007).	Thank you for your comment. We have restructured this section as you suggest.

British Psychological Society	Short	4	General	The Society believes that recognition of and responses to meeting the challenges within services to provide suitable care with limited budgets would be helpful here. (Age UK, 2014) *Care in crisis;* (The Kings Fund, 2016)	Thank you for your comment. We have noted the pressure on services in the first paragraph of this section.
British Psychological Society	Short	7	General	The Society believes that seeking input from specialist Speech and Language Therapists where available (e.g. where there are available as part of specialist community learning disabilities teams) should be included. This would assess communication needs / changes in these, and provide recommendations to support communication needs.	Thank you for your comment. The committee recognises the important role played by speech and language therapists and endeavoured to reflect this throughout the guideline. However in light of your comment they agreed to make an additional reference in 1.1.5, which now recommends 'Seeking advice from, or referring people to a speech and language therapist whenever needed'.
British Psychological Society	Short	9	18-21	The Society believes that it important to include this specific guidance: It is likely to be the case that due to their individual needs and pre-existing cognitive and functional impairments as a result of their learning disabilities, older people with learning disabilities suspected of dementia will additionally need specialist input from professionals who are trained in specialist assessment and support of people with learning disabilities to support mainstream services' assessments of dementia and provision of appropriate support (BPS, 2015). Therefore, specialist learning disabilities services / professionals and mainstream services with specialism in supporting older people, should work together to provide the most appropriate assessment and support.	Thank you for your comment. The committee agrees with the point you make but on reflection they felt it is already covered in recommendation 1.2.10, which promotes links between specialist learning disability and mainstream older people's services.
British Psychological Society	Short	10	21	The Society welcomes people with learning disabilities accessing mainstream services whenever possible, however in practice there are some barriers to this. For example, many of the cognitive assessments used in mainstream memory clinics are not appropriate for use for people with learning disabilities (e.g. because they are too complex at baseline, producing floor effects and a lack of sensitivity to change in presentation). We believe it would therefore be helpful to add an additional statement to emphasise the need for clearly commissioned pathways when specialist learning disability services are needed. For example, If there is a need for some older people with learning disabilities to access specialist learning disability services for some aspects of their health care (e.g. for specialist assessment of dementia that can account for a person's baseline cognitive difficulties) then this should be part of a clearly agreed and commissioned pathway.	Thank you for your comment. The committee discussed the point you raise and they feel it is adequately covered in recommendation 1.2.8 and also in 1.2.10 about establishing links between specialist learning disability services and older people's services, which would include dementia services.
British Psychological Society	Short	12	9	The Society welcomes this and believes that difficulties have arisen as a result of such diagnostic overshadowing. We believe that it is also important for practitioners conducting assessments to have expertise in the area of learning disabilities as well as issues relating to older age. This is to ensure that consideration can be given to specific issues relating to the learning disabled population and specific initiatives (e.g. annual health checks). The Society would welcome an additional sentence or paragraph emphasising this,	Thank you for your comment. In order to strengthen reference to diagnostic overshadowing in the guideline, the committee agreed to specifically cite 'diagnostic overshadowing' in recommendation 1.3.4 and to also define the phrase in 'terms used' to which there is a direct link from the recommendation. In the same recommendation they also added an opening sentence, which reads, ' Be aware that people growing older with learning disabilities might have difficulty communicating their health needs'. In addition, in recommendation 1.7.3 about training for staff working with people with learning disabilities, the committee added

				perhaps by noting the need for practitioners to recognise when they might need to refer to specialist services.	'knowledge about the potential for diagnostic overshadowing. We hope these changes help to address your concern.
British Psychological Society	Short	16	3	The Society welcomes the work NICE has done in recognising the role of family and carers in people's lives. We believe that adding 'friend' or 'supporter' to "family member or carer" to fit with the person's circumstances/wishes would benefit the guidance. This recurs in the following pages. Although 'carer' is defined as 'others who provide support including friends' (p26, line 25), friends and peers may not consider themselves 'carers'. In addition, friends who have a learning disability may easily be excluded from events in their friend's life/ person with a learning disability may not be able to communicate easily their wish for a friend to accompany them/ professionals may not include friends if not directly involved in that person's care. (Lynggaard, H. & Alexander, N., 2004)	Thank you for your comment. We have revised recommendation 1.5.1 to include 'advocate'. In addition to family carers, we also added supporters, friends and advocates in other recommendations, which relate to supporting people with learning difficulties, according to the wishes and preferences.
British Psychological Society	Short	17	11-15	The champion should also ensure good links between mainstream older people's and specialist learning disabilities services. Mainstream services are likely to require the expertise of specialist learning disabilities services to provide appropriate assessment and support.	Thank you for your comment. The committee felt that it was implied that the champion would share good practice within the context of all the care and support being offered to people with learning disabilities. They also feel your point is addressed in 1.2.10, which recommends that commissioners and providers establish links between specialist learning disability and mainstream older people's services.
British Psychological Society	Short	17	21	The Society welcomes this section and believes that it provides an important reminder that people with learning disabilities should be given access to routine screening and health checks – at present there are often barriers to this. We believe that it would be helpful to emphasise that commissioners should ensure that reasonable adjustments are offered for routine screening and health checks so as to ensure that people with learning disabilities are able to access them (e.g. extended appointments, appropriately resourced LD liaison nurses or specialists who can support relevant screening etc.).	Thank you for your comment and your support. We have revised the recommendation making reference to person-centred 'reasonable adjustments' (1.13) and 'extended appointments' in recommendation 1.1.5.
British Psychological Society	Short	24	27	The Society believes that additional statement should be included to reflect the need to increase the flexibility of packages of care at end of life when an individual's needs may change rapidly. For example – short term additional funding may be required to support that individual at home and prevent hospital admission. (National End of Life Care Programme, 2011)	Thank you for your comment, with which the committee agree. However, funding issues are not within the remit of this guideline so we are unable to make this change.
British Psychological Society	Short	25	9	The Society believes that an additional section is needed here stating that all staff should have knowledge of the causes of early mortality in people with learning disabilities and that there should be process in place to learn from deaths or serious incidents. For example an extra bullet point could be added stating: • The main causes of early death in people with learning disabilities. Staff should also have access to processes allowing them to learn from Learning Disability Mortality reviews and any serious incident reviews relating to health and social care provision for older people with learning disabilities.	Thank you for your comment. This is now added to the recommendation.
British Psychological Society	Short	25	9		Thank you for your comment.

				The Society believes that it would be helpful to stress the importance of having the appropriate skills and knowledge to safeguard older adults with a learning disability. A bullet point could be added: • Specialist knowledge and skills in recognising and alerting the risks to people with a learning disability who are older and/or who are experiencing age related conditions	Issues on safeguarding are now added to this recommendation
British Psychological Society	Short	25	21	The Society welcomes NICE's recognition of the workforce skills and expertise needed in supporting older adults with learning disabilities. The Society feels that reference to specific joint working between mainstream older people's and specialist learning disabilities services would ensure the expertise of professionals with specific knowledge in the assessment and support of people with learning disabilities is incorporated.	Thank you for your comment. The committee considered these points and believe they are already addressed in recommendation 1.6.8 in the draft recommendations.
British Psychological Society	Short	25	24	The Society believes that NICE should include a section about supporting the emotional and psychological needs of paid care staff. For example, this is particularly relevant where staff have known the person for many years, and where they are experiencing the loss of that person as they develop dementia, other age related conditions, or are at the end of their life. This support could be provided through supervision from the community learning disability team, or via referral to mainstream IAPT services. (https://www.england.nhs.uk/wp-content/uploads/2017/08/delivering-end-of-life-care-for-people-with-learning-disability.pdf).	Thank you for raising this. It is an interesting point and one, which the committee had discussed during development. However unfortunately, it is not within the scope of NICE guidance to tell organisations what support they should be providing to their own staff. We are therefore unable to make the change you suggest.
British Psychological Society	Short	27	13	The Society recommends clarifying the age range for older people with learning disabilities in this guideline as the social needs are likely to be needed at a younger age, which will impact upon the ability for mainstream services to meet needs appropriately using existing resources. For example, it is noted (pg 4, 12) that older people with learning disabilities may be likely to move into residential care younger than the general population. While the Society feels that the absence of a chronological age barrier is helpful in opening up access to services, clear guidance on age would be beneficial in terms of commissioning. **References** Ball, S.L., Holland, A.J., Huppert, F.A., Treppner, P. & Dodd, K. (2006). *CAMDEX-DS: The Cambridge examination for mental disorders of older people with down's syndrome and others with intellectual disabilities.* Cambridge: Cambridge University Press; British Psychological Society (2014) *Clinical Psychology in the Early Stage Dementia Care Pathway.* Leicester: British Psychological Society; British Psychological Society (2015) *Dementia and People with Intellectual Disabilities.* Leicester: British Psychological Society;	Thank you for your comment. The work to develop the guideline scope – which included a stakeholder consultation - gave support to the approach of not using a specific age cut off to define 'older'. This is in recognition that adults with learning disabilities typically experience age-related difficulties at a younger age than the general population, and that the onset of age-related difficulties will vary from person to person. The Guideline Committee considered this issue again following consultation. Given the considerations above, they have decided to stay with their original position. The title of the guideline has been amended to reflect the fact that the focus of the guideline is about the process of ageing, rather than 'older age' per se. We also thank you for providing these references, which we have investigated by referring to our original search and screening to understand why they were not included in our review. Ball et al (2006) This publication (book) was located by our search but excluded because the topic is not within the scope of this guideline British Psychological Society (2014) This publication was excluded as it relates to care-pathway of dementia care which is out of scope of this guideline British Psychological Society (2015) This was excluded as it is a policy and practice guidance, and not a primary study

				The Kings Fund (2016) *Social Care for Older People: Home Truths. (Online) the kings fund website https://www.kingsfund.org.uk/sites/default/files/field/field_publication_file/Social_care_older_people_Kings_Fund_Sep_2016.pdf*). Lynggaard, H. and Alexander, N. (2004), 'Why are my friends changing?' Explaining dementia to people with learning disabilities. British Journal of Learning Disabilities, 32: 30–34. doi:10.1111/j.1468-3156.2004.00246.x National End of Life Care Programme (2011) The route to success in end of life care - achieving quality for people with learning disabilities. http://webarchive.nationalarchives.gov.uk/20130718121128/http://www.endoflifecare.nhs.uk/search-resources/resources-search/publications/imported-publications/the-route-to-success-in-end-of-life-care-achieving-quality-for-people-with-learning-disabilities.aspx; Tyrer, F., Smith, L.K ., McGrother, C.W., Taub, N.A. (2007) The impact of physical, intellectual and social impairments on survival in adults with intellectual disability: a population-based register study J Appl Res Intellect Disability, 20, 360-367 Worley, G., Crissman, B.G., Cadogan, E., Milleson, C., Adkins, D.W. & Kishnani, P.S. (2014). Down syndrome disintegrative disorder new-onset autistic regression, dementia, and insomnia in older children and adolescents with Down syndrome. *Journal of Child Neurology*, 0883073814554654.	The Kings Fund (2016) This was not located by the search because the term 'older people' did not appear in the title or abstract. Lynggaard et al (2004), This was t excluded on 'date' (10 year search period criteria). National End of Life Care Programme (2011) This was excluded on 'policy and practice guidance'. Tyrer et al (2007) This wasexcluded as it did not relate to any of our review questions, ie. out of scope of our guideline Worley et al (2014). This was not located by the search because the term 'older people' did not appear in the title or abstract.
British Psychological Society	Short version	9	3	The Society recognises the key role that high quality data has in the planning of local services, and welcomes the principles behind this statement. However, we believe that the paragraph oversimplifies the challenges relating to identifying the number of households that include an adult with a learning disability - current learning disability registers and data sets contain a number of errors and omissions, and most people with a learning disability are not known to specialist services. The Society therefore believes that it is important for the NICE guidance to highlight that there might be significant cost implications (i.e. through a need for specific additional investment) to develop good quality data in this area. https://www.gov.uk/government/publications/people-with-learning-disabilities-in-england-2015	Thank you for highlighting this. The committee recognised and acknowledge the cost implication this will entail. We anticipate that this recommendation will initiate important discussions on these issues between the different parties concerned.
Care and Repair England	Short	General		We welcome the inclusion of housing and housing circumstances in this guidance and suggest some areas where references to the housing needs of older people with learning disabilities could be enhanced.	Thank you for your comment. We have responded to your specific points below.
Care and Repair England	Short	4	18	Add health and social care and related **housing** needs	Thank you for your comment. The principal focus of this guideline is on care and support of people with a learning disability as they grow older. However, housing support needs are referenced in the next sentence which outlines the scope for the guideline, and are covered in recommendations 1.1.3, 1.1.6, 1.2.4, 1.2.5, 1.4.6, 1.4.7 and 1.4.8 to 1.4.13.
Care and Repair England	Short	9	24	Add equipment**, access to repairs** or housing adaptations	Thank you for your suggestion. The committee discussed your point at length and concluded that the practical reality of always adding 'repairs' to the recommendations about equipment would actually be

					too contentious because damage or the need for repairs could in some circumstance be the person's own responsibility to resolve.
Care and Repair England	Short	10	10	Add to the list Access to home repairs and adaptations services	Thank you for your suggestion. The committee discussed your point at length and concluded that the practical reality of always adding 'repairs' to the recommendations about equipment would actually be too contentious because damage or the need for repairs could in some circumstance be the person's own responsibility to resolve.
Care and Repair England	Short	12	15	Add asking people where they would like to live?	Thank you for your comment. The importance of asking people where they wish to live now and in the future and enabling them to fulfil those wishes is already covered by the recommendations, for example recommendation 1.4.8 and the others relating to future housing.
Care and Repair England	Short	14	19	Add housing adaptations**, repairs** and technology	Thank you for your suggestion. The committee discussed your point at length and concluded that the practical reality of always adding 'repairs' to the recommendations about equipment would actually be too contentious because damage or the need for repairs could in some circumstance be the person's own responsibility to resolve.
Care and Repair England	Short	15	13 – 14	Add **repairs** after telehealth monitoring	Thank you for your suggestion. The committee discussed your point at length and concluded that the practical reality of always adding 'repairs' to relevant recommendations about would actually be too contentious because damage or the need for repairs could in some circumstances be the person's own responsibility to resolve.
Care and Repair England	Short	15	21	Add a new section that covers when moving to a specialist housing or another housing setting and include the same issues as in the section on moving to residential care	Thank you for your comment. We have amended recommendations 1.4.12 to 1.4.13 to clarify this point. The recommendations now refer to moving from where people 'currently live' rather than any specific reference to residential care. We hope this addresses your point.
Care and Repair England	Short	28	17	Add local health, social care **and housing** services	Thank you for your comment. This addition has been made.
Care and Repair England	Short	30	11	After assistive technology add **adaptations and equipment**	Thank you for your suggestion. A gap in the evidence about assistive technology (telecare, telehealth) was identified and this explains the focus of this research recommendation. The guideline committee did not believe there was a particular reason to develop a research recommendation about the effectiveness of adaptations and equipment.
Care and Repair England	Short	30	17	Add we do not have evidence of the impact of adaptations and equipment to support people at home	Thank you for your suggestion. A gap in the evidence about assistive technology (telecare, telehealth) was identified and this explains the focus of this research recommendation. While it may be true that there is also a lack of evidence about adaptations and equipment to support this population at home, the guideline committee did not believe there was a particular reason to develop a research recommendation about its effectiveness. The committee are limited in the number of research recommendations they can develop and therefore have to prioritise on the basis of discussions stemming from the evidence review and their own expertise.
College of Optometrists	Short	General	General	The College of Optometrist would like to thank NICE for this guideline and for the opportunity to comment. We welcome the inclusion of eye health as a consideration for health and social care professionals, family members and carers when providing care and support of older people with learning disabilities.	Thank you for your comment, and for your support for the guideline. Reference to sight tests was also added to recommendation 1.5.17.

				Sight loss is a severe disability and can have a devastating pervasive effect on all aspects of life. There is a link between sight loss and reduced wellbeing. Patients with learning disabilities may have additional ocular conditions and other health problems.	
College of Optometrists	Short	10	15-17	We support this recommendation. We would stress the importance of interventions that encourage regular eye examinations with an optometrist as important healthy lifestyle behaviour. The vast majority of cases of sight-threatening, non communicable eye diseases are detected through eye examinations by optometrists and early detection is a key factor in improved patient outcomes. The College of Optometrists has published a Guidance for professional practice, which includes a section on "Examining patients with learning disabilities". http://guidance.college-optometrists.org/guidance-contents/knowledge-skills-and-performance-domain/examining-patients-with-learning-disabilities The Guidance provides recommendations to support Optometrists when examining a patient with learning disabilities.	Thank you for your comment, and for your support for the recommendation. We will pass this guidance on to the NICE endorsement team. In addition, please note that we have amended a number of recommendations to place greater emphasis on monitoring and management of sight problems among our guideline population. . We have amended recommendation 1.5.17 to make reference to informing people about, and helping them to access, sight tests. With regard to commissioning, recommendation 1.2.7 states that commissioners should identify gaps in community optometry services. In addition, 1.5.14 under 'health checks and screening' recommends that practitioners ask people about and monitor people for symptoms – with hearing loss and sight problems at the top of that list of examples, Finally, 1.5.6 recommends that training is commissioned for people and their families to help them recognise and manage age related conditions, again with hearing and sigh loss and the top of the list of examples,
College of Optometrists	Short	16	20	The College of Optometrists supports this recommendation. Thanks to the frontline nature of the profession, and the high levels of patient coverage, optometrists are in a fortuitous position to help people and their family members and carers in recognising and managing age-related eye conditions.	Thank you for your support.
College of Optometrists	Short	18	1	The College of Optometrists supports this recommendation. See our comment above.	Thank you for your support.
Department of Health	Short	General	general	We have read the short version of the guideline and are happy with the recommendations. Thank you for producing the draft guideline on Care and support of older people with learning disabilities.	Thank you for your comment, and for your support for the guideline.
Dimensions	Short	General	General	We support proposed NICE guidelines for older people with learning disabilities. As a major provider of support and housing to people with learning disabilities, we want to enable the people we house and support to remain living where they live, surrounded by people that care about them into old age and death, where possible. Guidelines that ensure that we work around people and their families to enable them to remain in their homes where possible are welcome. To enable a person with dementia or other conditions relating to ageing to remain in their home might require providers to have new and better skills to support them, or some adaptations or assistive technology, or a higher level of support… it does not always require a move and in some cases a move would be the worst solution for the individual. Promoting a person centred, flexible and sometimes	Thank you for your comment, and for your support for the guideline.

				creative approach to support older people with learning disabilities needs the commitment of the family, provider and commissioner to work with the person to help them get what they want and need. The approach in these guidelines is welcome.	
Dimensions	Short	General	General	Question 2: We believe the following will have the greatest cost implication: • Providing adequate support to family carers Adaptations to people's homes • Skills for age-related care and support Carving out time and personnel to coordinate care and support around age related conditions	Thank you for your comment. The Guideline Committee considered carefully the resource impact of the recommendations and acknowledge the challenges involved in implementing them. The recommendations are considered to be aspirational but achievable and for example, in terms of supporting family carers the GC considered that this investment would help to prevent a crisis or break down in a care and support relationship, potentially resulting in costly hospital or long term care. In relation to investment in home adaptations, again the GC considered that this upfront investment would ensure the person remain living in their place of choice, and that with the necessary support or equipment, this would be sustained over a longer period, avoiding more costly hospital or long term care.
Dimensions	Short	General	General	We highlight the following as existing resources and examples of good practice • BILD and the Foundation for people with learning disabilities' work to support people with learning disabilities and their families with aging – in partnership with the National Valuing Families Forum • The Downs Syndrome Association have a comprehensive dementia support guide which is easily adaptable to other people with learning disabilities • National Development Team for Inclusion have done extensive work in this field The Palliative Care for People with Learning Disabilities network provides good information on end of life support http://www.pcpld.org/	Thank you for your comment. We will share these with NICE's endorsement team.
Dimensions	Short	1 - 4	5	It is important that working aged adults with learning disabilities continue to be treated as such within services, even as they develop conditions that may be considered age related. We are concerned that, without a more specific guideline on this, working aged adults with learning disabilities can be side-lined into older people services. For those conditions that do require shared pathways with older people's services, such as for early onset dementia, services should be mindful that someone in the forties has different needs and these should be acknowledged and respected.	Thank you for your comment. The referral from the Department of Health and Social Care was specifically for NICE to develop a guideline about care and support for older people with learning disabilities. We will feed back that there may be a gap in terms of a guideline for working age adults. You will have noticed that we have not used a strict age cut off for our definition of 'older people' and this is in recognition of the point you make that people with learning disabilities often experience age related conditions at an earlier stage in life. We are clear that this guideline applies to those people. In particular we have specific recommendations on people with dementia and a recurring message within the whole guideline is to ensure that support is person centred, suited to people's individual preferences and is age appropriate. Finally, in order to emphasise our broad concept of older people within this population, the committee agreed to change the title of the guideline to 'Care and support of people growing older with learning disabilities'. Please note that NICE has been referred a topic from DHSC on Adults with complex needs (including learning disabilities) and mental health needs: social work interventions. Work on this new guideline will start in the next year.

Dimensions	Short	1	16	We note that older people with learning disabilities typically have reduced financial security and may be impacted more severely by food and fuel poverty, leading to risks to health.	Thank you for your comment. The context section for the guideline now highlights that the health of people with learning disabilities may also be impacted by social factors such as diet.
Dimensions	Short	1	24	Practitioners should look to include friends at the end of people's lives, including those they may have lived with in the past.	Thank you for your comment. Recommendations 1.6.6 to 1.6.13 address involving family, carers and advocates (which would include friends) in end of life care.
Dimensions	Short	3	8	Particular attention should be given to building links with siblings that may have been lost from the system when the person's parents die.	Thank you for your comment. Encouraging older people to build and maintain links with family is covered in recommendation 1.3.5.
Dimensions	Short	12	9	Day opportunities should be age appropriate, so that working aged disabled adults use services for their age group, where appropriate. Steps should be taken to ensure that older people's services are inclusive and that attitudes towards people with learning disabilities are inclusive.	Thank you for your comment. We have considered this and inclusiveness based on people's preferences, choices and abilities are addressed in recommendations 1.2.9 to 1.2.13.
Dimensions	Short	28	11	Assessments should be compliant with the Care Act	Thank you for your comment. The point you make is of course true, and the context section of the short guideline identifies the Care Act as one of the pieces of legislation that will inform practice in relation to this guideline. But there is no direct reference to assessment in the paragraph (which is primarily about being person-centred) and the Guideline Committee have reviewed it and beyond adding a sentence about annual health checks, they didn't feel anything needed to be added.
Dimensions	Short	29	9	We highlight those living in accommodation with older relatives where the tenancy or ownership will not pass to the person, leaving them in unstable housing.	Thank you for your comment. In terms of making any changes to the text, we are unable to do this because it is standard to all NICE guidelines.
Dimensions	Short	15 – 17	10	Clinical Commissioning Groups should also look at gaps in audiology and give particular attention to podiatry, physio and equipment to maintain mobility and postural care.	Thank you for your comment. We did not identify any evidence supporting audiology, podiatry and physiotherapy to maintain mobility and posture care. However, the Guideline Committee is limited in the number of research recommendations they can develop and therefore have to prioritise on the basis of discussions stemming from the evidence review and their own expertise.
Dimensions	Short	18 – 19	16	Resources for training around age related conditions should be agreed with commissioners to ensure there is adequate funding.	Thank you for your comment. Unfortunately funding is out of scope of this guideline so it is not possible to include this degree of detail in the recommendations. It is the responsibility of clinical commissioning groups to ensure resourcing for training.
Dimensions	Short	26 – 30	10	Question 1: This recommendation will be a challenging change in practice because older people's services in the mainstream are not used to working with people with learning disabilities as health inequalities have prevented people from reaching old age. For the next couple of decades, older people will be unused to inclusive environments so there will be work to do to change attitudes.	Thank you for this response. The guideline committee recognises these issues, which they have endeavoured to address through the recommendations, particularly those promotingjoint working and sharing of expertise, for example 1.7.4 .
Durham County Council	Short	general	general	Durham County Council believes that the areas which may have the biggest impact to practice are Communication: • Use and availability of visual aids • review the communication needs Decision making and mental capacity Service users participation essential Organising and delivering services – identifying all households that include an adult with a LD – potentially difficult to implement Combining personal budgets with other family members may be difficult to navigate where different social workers/teams are involved.	Thank you for this information, which we will pass to our endorsement team. Thank you for your comment about the difficulties associated with combining personal budgets, which the committee discussed. While they acknowledged the challenges, committee members felt that the point of the recommendation was to encourage teams to work together and that if this happened and along with careful planning, the recommendation is indeed possible and achievable. They therefore agreed to retain the recommendation. Thank you for highlighting this. The Guideline Committee agrees with you and they believe the point is clearly made in draft recommendation 1.1.8.

				Emphasis should be involving the individual as far as possible in decision making, even if they lack mental capacity.	
Durham County Council	Short	general	general	Durham County Council have identified possible cost implications: • Visual aids • Organising and delivering services • Identifying the number of households that include an adult with a learning disability. • Housing options, arranging housing for older people with LD who are in unstable housing situations: • Free travel • Increased cost due to further specialist support for example a person with a learning disability who then develops mental health problems	Thank you for your comment and the information provided, which will be passed to our endorsement and resource impact teams.
Durham County Council	Short	general	general	Durham County Council the paper reflects of positive practice and we would aim to comply with draft guidelines. Those in receipt of services from the Learning Disability Teams would continue to do so through to old age and as an integrated team this would assist with the health focus. For those who have mild learning disability and who may not fulfil the criteria for services through the learning disability teams, they would be assessed and receive services through the Older persons Teams/Physical disability Teams	Thank you for your support. It would be most helpful if you could let us know your experience of implementing this guideline so that other services can share what you have learned.
Hampshire County Council	Short	7	1.1.8	The team noticed that not much focus throughout the document related to advance decision making and DOLs/ MCA decision making.	Thank you for your comment. The committee agrees that decision making and mental capacity is particularly pertinent to this guideline population and they have made several references to important principles throughout the guideline (for example, in 1.1.8, and the new 1.1.11). However they are also mindful of the fact that NICE will shortly publish a guideline entirely focussed on ‘Decision Making and Mental Capacity’ so to avoid duplication, people are encouraged to refer to that guideline. In addition, the context section has been amended to specify legislation which is relevant to this guideline and that includes the Mental Capacity Act 2005.
Hampshire County Council	Short	12	1.3.6	As a team we discussed that often the cared for person has different views about the care and support provided from the carers. We often have to balance these wishes against carers views and wishes. This is not reflected in the document.	Thank you for your comment. The committee is aware of these dilemmas and endeavoured to address them in the recommendations. For example, the committee highlighted the importance of people’s views not being overshadowed by the preferences of people around them, even when they lack capacity. The committee recognises the important role of advocacy in balancing the needs and wishes of people and their families and they wished to strengthen the focus on this. In agreeing the final guideline, they therefore adopted and adapted a recommendation from the NICE service models guideline about offering independent advocacy wherever it is wanted or needed.
Hampshire County Council	Short	13	1.4.2	Transport of cared for people if often not realistic and we focus on solutions within the community network.	Thank you for your comment. Recommendation 1.214 is not intended to imply that local authorities fund all those suggested transport services, just that consideration should be given about

					meeting people's transport needs with the examples listed being a range of options derived from the evidence and from the committee's expertise and experience about existing schemes. The committee felt that local authorities should be encouraged to take a creative approach to transport solutions, building on existing schemes and/ or working with voluntary providers.
Hampshire County Council	Short	23	1.6.2	Often LD social workers are not asked by health colleagues to continue to support a client after CHC fast track has been awarded.	Thank you for your comment. The committee anticipate that these recommendations will encourage more joint working, which is centred around the individual and therefore lead to positive changes in this respect.
Hampshire County Council	Short	25	1.7.3	The team reflected that often we have never been provided training in palliative care pathways and that only BIA challenge DNR status which is normally agreed with a doctor and family. This is not common practice to challenge but we feel that it should be challenged and that social care practitioners should be able to do so if there are concerns about the way in which it had been agreed.	Thank you for your comment. It is intended that the guideline will be used in local areas for discussion between local authorities and clinical commissioning groups. In this sense we anticipate the recommendations will initiate positive changes in terms of shared learning between health and social care and increased confidence in the application of the Mental Capacity Act 2005 and Code of Practice. .
Hampshire County Council	Short	25	1.7.4	The team felt that generic adult services practitioners often lack the skills required to work effectively with LD commissioners.	Thank you for your comment. We anticipate the detailed training recommendations will initiate positive changes in practice.
Healthcare Inspectorate Wales	Short	General	General	Overall, the guideline is comprehensive, detailed and founded on both sound principles and good research evidence. As with anything of this nature, it is relatively easy to describe the objectives, less easy to explain how busy practitioners and leaders can achieve those goals. For this reason it could be helpful to make better links to NICE's 'into practice' material throughout the guideline (it is referenced at the end of the main document). With the exception of one reference to research, the guideline is notably silent on the Wales context. This is a gap, given that the legislative context for health and social care in Wales is separate and different to that which applies in England. The section on communication, for example, makes no reference to the need to respond to people's language of need, including in Welsh if necessary. Learning from HIW's National Review and inspection activity HIW's Learning Disability thematic report for 20151-16 was published in 2017. http://hiw.org.uk/docs/hiw/reports/161208ldreviewen.pdf The report found a significant shortfall in the ability of health boards - and their partners - to turn strategic intention into practical plans for change that result in positive outcomes. The report notes, for example, that, *health boards had identified that they had a growing population of older people with a learning disability. However, they had not moved on to considering what additional or different service provision might be required such as providing services for people with learning disabilities and dementia.* (p27). There is then, much to be done in Wales to achieve the aspirations in the guideline for assessing need and planning for the future. Our report also noted that the issue of consent was repeatedly being overlooked in NHS residential units in Wales. We welcome, therefore, the discussion of this issue in the guideline. However, while the guideline explores capacity and consent, it does not place these issues in the context of Safeguarding. This is a significant gap. Older people with learning disabilities are no less likely to be at risk of abuse than any other section of the population – indeed, they are	Thank you for your comment. It is usual NICE house style for the 'into practice' material to be available at the end of the document, and also via hyperlinks on the guideline web pages. The way NICE was established in legislation means that NICE guidance is officially England only. Decisions on how NICE guidance applies in Wales, Scotland and Northern Ireland are made by the devolved administrations. However, the guideline principles of good quality, personalised support are likely to support translation to other jurisdictions. We have strengthened the references to safeguarding in the guideline by: - including reference to safeguarding in the introduction, including stating that practitioners must follow local safeguarding procedures - adding in reference to recommendation 1.1.6 to providing people, and their families, carers and advocates with information about safeguarding procedures - adding in reference to recommendation 1.7.3 about training for staff.

				likely to be more vulnerable. The guideline should, at the least, make the appropriate links to Safeguarding guidance.	
Healthwatch Cumbria	Easy Read	general	general	- The Group [Barrow Self-Advocacy Group] agreed and supported all the guidelines. But did identify some challenges/pressures: - Ensuring inter agency sharing of information - Ensuring consistency of support methodology across agencies to minimise stress and worry for the person with LD - Budget pressures and lack of locally available resources can be a barrier to address the person's wishes or needs - Willingness of families to agree to the individual's choices (may consider unwise) - Availability of readily available generic Advocacy (Care Act Advocacy and Mental Capacity Advocacy are for specific purposes)	Thank you for your comment, and for your support for the guideline. We hope that the guideline will support good practice in relation to the areas you highlighted: - Information sharing is covered in the section on 'Coordinating care and sharing information' - Consistency of support should be helped by the recommendations in the 'Care planning and review' section - When and how to involve families is covered by the recommendations in the section on 'Involving people and their family members, carers and advocates'. With regard to budget pressures, the Guideline Committee considered carefully the resource impact of the recommendations. The recommendations are considered to be aspirational but achievable. It is also important to note that, under the Care Act, local authorities must meet the needs of adults with eligible needs, but that there may be a variety of approaches to achieve this. With regard to advocacy, this is a weaker 'consider' recommendation, to reflect the fact that this is not a statutory right, and that there was not strong evidence to support this.
Healthwatch Cumbria	Short	general	general	I approve of its content, with its recognition of adults with LDs' human rights, concern to address the wide range of presenting difficulties, awareness of the intense pressures put on often ageing family carers, concern for a sympathetic and full response from health and care services, mention of the need for a 'single lead practitioner'. To me, the guidelines seem clear and realistic. Looking at the document from an editorial perspective – there needs to be a slight re-write of paragraphs 1.6.2 through to 1.6.13 (probably with the greater use of bullet points and renumbering of sub-paragraphs). I suggest 1.6.2 introduces the range of recommendations as follows - '1.6.2 Practitioners providing end of life care should: [colon!] ...' [then list what they should do] This would achieve greater stylistic consistency and would be more grammatical.	Thank you for your comment and for your support. Having considered your suggested edits, the committee felt that on balance the recommendations should be left as they are in other stakeholders interpretation, not least because there don't appear to have been any issues in stakeholders' interpretation of them.
Home Group Ltd	Short	General	General	Overall Home Group welcomes the development of this new guidance. Home Group's approach to supporting older people with learning disabilities is already aligned to key principles such as person-centred care, meeting changing needs and promoting choice and control. This guidance will help enable community social care providers like Home Group, and the people we support, to hold services to account and to promote and encourage best practice.	Thank you for your comment, and for your support for the guideline.
Home Group Ltd	Short	15	11 - 15	We welcome the focus on making reasonable adjustments to help people stay in their own homes for longer. As a national homes builder, Home Group already takes steps to consider the needs of people as they grow older in building design and adaptations. The draft guidance has been useful in prompting consideration of adjustments that may be needed by older people with learning disabilities in addition to the general population of older people.	Thank you for your support.
Home Group Ltd	Short	17	20	Home Group has experience of providing 'health coaching' and implementing national healthy living initiatives such as social	Thank you for your comment and the information provided. Unfortunately the systematic review did not locate any evidence

				prescribing and Making Every Contact Count as part of our New Models of Care re-ablement offer. We would be willing to share our experiences of these initiatives to the NICE shared learning database. Contact	about this model and given that they cannot develop recommendations about particular models or approaches without supporting evidence, the committee was unable to develop a recommendation with this specific focus. However, we will pass the information to the endorsement team.
Home Group Ltd	Short	25	1 - 20	Whilst we welcome the approach outlined in the guidance to ensuring that staff working with people with learning disabilities develop appropriate skills and knowledge, this will be dependent on the availability of appropriate training provision. As noted in the guidance, workforce development products for staff working with older people tend to be developed and offered separately from workforce development products for staff working with people with learning disabilities. We would like to see more integration in the products offered by social care training providers as well as support to develop 'in-house' provision in order to fully meet standards outlined in the draft guidance – for example, resources aligned to the Dept of Health Learning disabilities, core skills, education and training framework.	Thank you for your comment. We agree that this is an important issue. However, the availability and organisation of appropriate training provision for different staff disciplines are not within the remit of this guideline. We anticipate the recommendation will initiate important discussion, leading to positive changes in practice.
Kent County Council	Short	11-12	23-29 & 1-18	All references to assessment should refere to needs assessment in line with the Care Act	Thank you for your suggestion. Instead of adding this to every recommendation that refers to assessment, the committee felt it would be clearer and less cumbersome to make a more explicit reference to the Care Act 2014 as well as other important legislation in the context section at the beginning of the guideline.
Kent County Council	Short	11-12	23-29 & 1-18	Assessment should be strengths based, there needs to be an additional paragraph which discussed the assessment of what the person is able to do, what community assets support them, we are discussing older people so they may well have a network of support or have been using particular community facilities which have supported them.	Thank you for your comment, which the committee found very helpful. In response they agreed to add 'strengths based' to the opening recommendation of the section on identifying and assessing care and support needs.
Kent County Council	Short	11-12	23-29 & 1-18	There possibly needs to be a section which includes prevention, reducing or delaying needs, so the section on assessment may need to be preceded by a section which explores how organisations support the person to remain independent of statutory services	Thank you for your comment. The committee discussed your point but they felt that within the confines of the guideline scope, reducing or delaying the need for care and support and promoting independence had already been well covered by the recommendations. For example, there are a number of recommendations focussed on living healthy lifestyles (1.2.12, 1.2.13, 1.3.5 in the draft guideline) and in the final guideline the committee agreed to emphasise the role of assessment in promoting independence.
Kent County Council	Short	4	5-6	It might be helpful to recognise that there may be some role reversal when a person with an LD becomes a carer for an aging parent/ former carer.	Thank you for your comment. We have reviewed this section, and think that the issue of people with learning disabilities becoming carers is adequately covered. This is also covered in recommendation 1.1.4.
Kent County Council	Short	4	9	Should this read' the person 'may' be inappropriately placed	Thank you for your comment. We have amended this section as you suggest.
Kent County Council	Short	6	6	'Give' older people access returns to the benevolent language of the state allowing people to have or do things. This should be reworded to indicate that Older people should have access to care and support which is tailored to their needs.	Thank you for your comment. The recommendations have all been reviewed to ensure the language is empowering and not benevolent. For this recommendation, 'give' has now been completely removed and replaced with 'Ensure older people with learning disabilities have the same access…' We hope this addressed your concern.
Kent County Council	Short	7	10	As above, this may need to read 'Older people with LD and their family members should have accessible information about:	Thank you for your suggestion. Having reviewed the language used in all the recommendations, the committee agreed to reword this to read, 'Provide people with learning disabilities, and their family members, carers and advocates…'

Kent County Council	Short	7	24	Should this section also include something more general which states that organisations should ensure information provided is freely available and meets the accessible information standards	Thank you for your suggestion. Having discussed your point, the committee agreed that it is adequately covered in recommendations 1.1.5 and 1.1.6.
Kent County Council	Short	9	To add in at line 19	It is vital that commissioners and providers facilitate building community connections and local relationships, to enable long term community support for individuals which will stop social isolation, and the likelihood of deskilling which often occurs following social isolation to gain regular human contact again. Relationship building should be a key premise of any support to aid long term support and cohesion for the individual.	Thank you for your comment. The committee agree with you about the importance of building community connections and they feel this is addressed in recommendations 1.2.9 and 1.2.11.
Kent County Council	Short	11	24	All references to assessment should be Care Act compliant and state 'needs' assessment, assessment should be holistic and strengths based.	Thank you for your suggestion. The committee discussed this point and agreed they would prefer to emphasise the Care Act along with other important legislation at the start of the guideline rather than mention it in individual recommendations, which they felt would be rather cumbersome and possibly detract from the important message. We have therefore added a section about relevant legislation which appears before the recommendations and which emphasises the legal and policy context within which these recommendations should be implemented. In terms of emphasising 'strengths based', the committee agreed to edit recommendation 1.3.1 accordingly and it now reads, 'Ensure that all assessments of care and support needs are strengths based, person centred and conducted as early as possible…' Finally, the committee did not agree to insert 'needs' in relation to assessment as this seemed to undermine the positive emphasis achieved by referring to 'strength based'.
Kent County Council	Short	11	24	There should be reference to ensuring people have access to Care Act advocacy in line with the Care and Support Statutory Guidance	Thank you for your suggestion. The committee agreed to adopt and adapt a new recommendation about ensuring access to advocacy under the Mental Capacity Act 2005, the Mental Health Act 2007 and the Care Act 2014. We hope this addresses your point.
Kent County Council	Short	15	21	There may need to application of the MCA and DoLS requirements, including CoP applications for moving home in a community setting or DoLS authorisation when moving into residential settings.	Thank you for your comment. Instead of addressing this in specific recommendations, the context section of the guideline now refers to the important legislative framework within which these recommendations should be implemented. This includes the Mental Capacity act 2005 and associated guidance on Deprivation of liberty Safeguards. These will be pertinent to a number of the recommendations, including 1.4.13. In addition recommendation 1.1.8 emphasises the importance of supporting people to make decisions and assessing capacity to make decisions with the requirements of the Mental Capacity Act.
Kent County Council	Short	16	1-2	Include consideration of using a 'My Health, My Life' diary type document to document health needs, interventions, support and treatment in a way which the person may understand and can share with professionals.	Thank you for your comment. Recommendation 1.5.2 states clearly that '…healthcare practitioners must take all reasonable steps to help the person understand this explanation'. Unfortunately the recommendations can't specifically cite the 'My Health, My Life' diary because the systematic review did not locate any evidence about it. The committee is unable to develop recommendations about specific tools or technologies without supporting evidence. We will however refer your suggestion to the NICE endorsement team.
Kent County Council	Short	16	18	Include professionals in the training needs for recognising age related conditions as they are ideally placed to make referrals to other services.	Thank you for your comment. The recommendation to which you refer is based on evidence about training and support for families and carers. Training needs for practitioners are addressed in recommendations 1.7.1 to 1.7.5.

Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees

Kent County Council	Short	17	16	Note the duty to share information for the purpose of Direct Care as set out in the Health and Social Care Act 2015	Thank you for your comment. The Guideline Committee took a decision to minimise the amount they cite specific legislation in the recommendations and instead have added a section to the 'context' to outline the legislative framework within which these recommendations must be implemented.
Mencap	Short	General	General	Whilst this is addressed throughout the document and particularly in lines 10-15, we would like more specific reference to the issues which face people with a learning disability and age related conditions. Namely that these conditions can become present in people with a learning disability at a younger age, but that the services that are developed to support people with these conditions are often developed with much older people in mind. This can lead to people with a learning disability using or even living in services that are inappropriate for them in many ways. It must be recognised that when people with a learning disability move to older people's services, even if they are age appropriate, there is often a lack of understanding about learning disability in these services leading to people receiving services and support not suited to them and having a range of unmet needs. Primary support for an individual must be identified and maintained if transitions are unavoidable. People who are already living in a supported environment can find themselves moved to an 'older persons service' when their needs change. Commissioners and providers must not forget that to the person, the service is their home and should be adapted if the person wishes to stay in their familiar environment. There may also be a tendency to regard it necessary to move people to a registered care environment rather than supported living if support needs increase. However, with the right commissioning and the right support package, a very high level of support can be given within the supported living environment.	Thank you for your comment. The Committee felt this is an important focus of the guideline. The findings of the evidence review highlighted the problems you described and from their own expertise - the Guideline Committee agreed there was a basis for recommendations about diagnostic overshadowing (1.3.4), about tailoring support to people's needs, strengths and preferences (1.1.2) providing appropriate accommodation (1.2.5), including adapting people's current homes (if this is what they would prefer) (1.4.6). The recommendation about diagnostic overshadowing has now been strengthened by including the term itself and by providing examples of it happening in practice. Thank you for highlighting this. It was a serious concern to the guideline committee and they developed recommendations to try to address this issue, for example about making reasonable adjustments to ensure services are fully accessible (in terms of age and disability, 1.1.3, about providing housing options to meet people's changing needs as they grow older (1.2.4), about ensuring a wide range of local support options to meet the needs of older people with learning disabilities and their families (1.2.5) and about planning for the future in a way which seeks to maintain the person's support and housing arrangements, if this is their preference (1.4.6).
Mencap	Short	11-12	22-18	Good practice is to take a baseline of people's behaviour and health – this way changes can be identified easily later on, minimising the risk of diagnostic overshadowing. This is particularly useful in diagnosing conditions such as dementia.	Thank you for your comment. The committee agreed to address your point by editing one of the recommendations in the section on assessment, which now highlights the importance of conducting '…person centred assessments as early as possible'.
Mencap	Short	12-13	19-6	Carers who are no longer able to provide care may also need emotional support. There should also be awareness that some carers may be new to this role as either someone with a learning disability gets older and needs more support, or stepping in to the role in place of an older relative who has previously acted as main carer. These carers may need different support from those who are more established and experienced. Ensure people with a learning disability have the support they need to cope with changes to care and support. Particularly bereavement support if an older family member acting as a carer passes away.	Thank you for your comment. The committee recognised these concerns and made recommendations to emphasise the need to have various resources available to support family carers to cope with caring for the person with learning disabilities (as in 1.2.3) Bereavement support is addressed in recommendations 1.4.4 and 1.6.12.
Mencap	Short	4	10-15	As above, more explanation needs to be given to the difficulties with inappropriate moves. We would like the last sentence to reference "communication, support and activities".	Thank you for your comment. We have amended this section as you suggest.

Mencap	Short	7	3-9	Regarding consent to involve family members and advocacy services – consent should be sought from people with a learning disability to both of these, however this section does not address those without capacity to consent and should be reworded to reflect the Mental Capacity Act.	Thank you for your comment, which the committee agrees is addressed in recommendation 1.1.8, which has been strengthened in the final version. In addition, a new recommendation on advocacy services has been adopted and adapted from the NICE service models guideline.
Mencap	Short	8	9	Ask the person who they want to involve regardless of whether they have close family members of not. Ensure that the involvement of family members, others and advocates is in accordance with the Mental Capacity Act.	Thank you for your comment, which the committee took on board. In the final version of the guideline, 1.1.10 recommends asking the person who they want to involve regardless of whether they have close family. The same recommendation also alerts practitioners to be aware that some people do not have close friends and family. For those who do not have close family members, friends or carers, or there may be family members who the person do not want involved, the committee ensured that people with learning disabilities have access to advocacy services (1.1.5, 1.1.11, 1.2.5). Many of our recommendations included advocates as one of the key members of the person's support network in decision making, accessing services and care planning.
Mencap	Short	9	3	Commissioners should identify the number of people with a learning disability in their area and family carers. This information is likely to be more helpful when planning services than the number of 'households'.	Thank you for your comment, which the committee has taken on board. In finalising the guideline, they edited recommendation 1.2.2 to read, 'Commissioners should identify the number of people…' (not households).
Mencap	Short	9	9-18	We feel this point would be better split into two: One to highlight the importance of age appropriate services Another to highlight the importance of resources and support for family carers. Please also include 'activities' in point 1.2.3	Thank you for your comment. The committee deliberately included support for families in this recommendation. The 'age-appropriate' element reflects the fact that family carers are likely to themselves be older so this recommendation has not been edited.
Mencap	Short	10	1-4	We would like this point to acknowledge people with a learning disability may already be living in a residential service or receiving community support. It is important to recognise that adaptations may be necessary to people's support as it exists to enable to them to keep living in their familiar environment (if they choose to) or maintain support from the people known to them.	Thank you for your comment. Committee members agree with your point and although they feel it is implied in other recommendations (such as 1.4.6 and 1.4.12) they agreed to edit recommendation 1.2.5 to say ' support to remain in their current accommodation (such as physical adaptations)'.
Mencap	Short	13	15	Flexible commissioning is to be encouraged as is support that is planned in a holistic fashion, taking all circumstances into account. However, the needs of the older person with a learning disability must be foremost when planning care and support for them and their support must not be compromised. Attention must also be paid to the potential for risks of increasing financial dependence on different members of the family and thereby threatening independence and autonomy by pooling support.	Thank you for your comment. The committee were well aware of protecting the needs and preferences of the individual while also respecting and involving families. Recommendation 1.1.12 specifically states that the needs and preferences of the person should be prioritised and not overshadowed by other people's preferences, even if mental capacity is lacking. Mutual caring relationships are also focussed upon in the recommendations to ensure that people's needs are assessed and met in the context of caring responsibilities and relationships they may have.
Mencap	Short	13	24-28	Constant access to information and advice is crucial for those supporting people with a learning disability as circumstance and needs can change quickly. Risks for individuals and those that support them should be identified early to avoid crises as these are not inevitable.	Thank you for your comment. The committee agrees with the point you make but feel that the recommendations already cover the provision of accessible, timely information and future planning before crises occur.
Mencap	Short	14	14	People's right to change their mind on decisions should be respected.	Thank you for your comment. Recommendation 1.4.6 makes reference to future planning to be 'led by the person themselves…' and 'reviewed every year and whenever the person's needs or circumstances change.' The committee therefore feels that your point is already reflected in the recommendation.

Mencap	Short	14	18	Including where people want to live and how current living arrangements could be sustained if the person wishes.	Thank you for your comment. The committee feels that this point is already covered in recommendation 1.4.6 which 'seeks to maintain the person's current support and housing arrangements, if this is their preference'.
Mencap	Short	14	25	Information on wills/trusts and benefits should be provided to families early on to plan for the future.	Thank you for your comment. We have amended the recommendations 1.1.6 and 1.4.7, making reference to wills and trusts and benefits.
Mencap	Short	15	1	Conversations/planning regarding end of life care and wishes are important. People should have the right to information about their health care and to know when they are approaching the end of their life. Processes should be in place to ensure this always happens. However, these kinds of conversations must happen when appropriate/necessary and be dealt with sensitively and in a way that is meaningful to the individual. The level at which these discussions take place will vary depending on an individual's circumstances and must be person centred. Individuals and those that are close to them will be able to indicate how much of a focus they want to give to thinking about the end of their life.	Thank you for your comment. The committee agrees that these issues are very important. They believe they are addressed in recommendations 1.6.2 to 1.6.13 relating to end-of-life care. Please note that we also make cross-reference to the NICE guideline on care of dying adults in the last days of life**.**
Mencap	Short	15	11	People may be living in residential care already. Adaptations to services must also be considered to allow an individual to continue living in the environment which they are familiar with and the staff that they know. Other residents may also need support to manage changes to people's support needs as they grow older.	Thank you for your comment. We have amended recommendations 1.4.12 to 1.4.13, with reference to 'where they currently live' to clarify this point.
Mencap	Short	15	General	Ensure that any accommodation that an individual is considered for is age appropriate.	Thank you for your comment. The committee considered your point and feel it is already addressed in recommendation 1.2.5. As with all of the recommendations in this guideline, they are underpinned with the overarching principle of person-centredness, including reasonable adjustments, in line with the Equality Act 2010. Age is one of the many individual characteristics considered fundamental to take into account when providing care.
Mencap	Short	16	General	Healthcare practitioners should consider whether an older person with a learning disabilities has unmet support needs, particularly support needs to help them manage their health. Referrals should be made to social care as necessary in addition to flagging support needs to other organisations as appropriate.	Thank you for your comment, a principle with which we agree. However it already seems to be covered in recommendation 1.5.15 (in the final guideline) so we have not made any changes.
Mencap	Short	16	9	Include other forms of communication, such as using objects, videos, easy read, role plays, talking mats etc. Use hospital passports, health action plans and other documents that can help individuals to communicate their health and support needs.	Thank you for your comment. Communication issues and techniques are addressed throughout the guideline, for example in recommendation 1.1.5, which we have revised to clarify how best to support the communication needs of older people with learning disabilities. The committee did not agree any further changes in light of your comment.
Mencap	Short	16	18	Include dementia as separate item and link to dementia pathways. Also dysphagia and incontinence.	Thank you for your comment. We have revised the recommendation 1.5.14 to include dysphagia, incontinence, and dementia as a separate bullet point. .
Mencap	Short	17	16	Include specific reference to additional information in Summary Care Records	Thank you for your suggestion. Having discussed it at length the committee decided not to recommend summary care records because in practice not everyone automatically or by default has access to one. They also felt that in the interests of future proofing the guideline it would be best not to introduce the concept.

Mencap	Short	18	1-10	Include dementia separate item and link to dementia pathways. Also dysphagia and incontinence.	Thank you for your comment. We have revised the recommendation 1.5.14 to include dysphagia, incontinence, and dementia as a separate bullet.
Mencap	Short	18	21	New figures from NHS Digital show screening for breast cancer has dropped among people with learning disabilities. Please highlight this in the guideline.	Thank you for your comment and for the additional information. We anticipate this recommendation will help people with learning disabilities to access health checks, including screening for breast cancer and therefore help to address this alarming trend.
Mencap	Short	19	20	Recognise that extra support may be needed for an individual to adjust to a health condition. Explore how this need may be met and make referrals as necessary to social care.	Thank you for your comment. The committee feel this is addressed in recommendation 1.5.15.
Mencap	Short	20	17	Be aware that a range of adjustments may be helpful to facilitate successful attendance at an outpatients appointment. Reasonable adjustments required on the day should be identified and also preparation work will need to take place. This may include visits to the department to meet staff, see equipment etc but also may include referral to learning disability liaison nurse, watching videos or providing easy read information, desensitisation visits etc.	Thank you for your comment. The committee feel that the points you make are already reflected in the recommendations, particularly 1.5.25 and others in the section on identifying health and managing health needs as well as in the overarching principles, particularly relating to the provision of information.
Mencap	Short	21	8	Hospital trusts should seek to make arrangements with the CCG and social care commissioners in their area to provide funding to allow for people's social care supporters to stay with them in hospitals where necessary.	Thank you for your comment. Unfortunately service organisation and funding are out of the scope of this guideline. The committee were unable to make any changes in light of your comment.
Mencap	Short	21	21	Discharge planning should begin as early as possible. Support may take time to set up and funding assessments may need to take place. Good communication with existing support providers is essential.	Thank you for your comment. These recommendations (1.5.32 to 1.5.36) are adapted from the NICE guideline on transition between inpatient hospital settings and communityor care home.This guideline is very clear about the need to start discharge planning as early as possible – even as early as admission needs. This seems to reflect the important point you make in your comment.
Mencap	Short	24	5	Everyone is able to communicate, however many people with a learning disability need a large amount of support or may struggle to communicate certain types of information.	Thank you for your comment. We've made changes in the recommendation to clarify this point.
Mencap	Short	24	General	Commissioners must recognise their role in funding support for services, family carers etc to be able to adapt to the amount of care that people may need at the end of their life.	Thank you for your comment. We have considered this. However, commissioning and funding issues are not within the remit of this guideline.
Mencap	Short	24	General	Palliative care referrals must be made in a timely fashion for all those that require it. CIPOLD (2013) found that people with a learning disability were less likely to receive referrals to the palliative care team and less likely to receive opioid analgesia.	Thank you for your comment. This is now addressed in the revised recommendations 1.3.1 and 1.6.1.
National Community Hearing Association	Full	General	General	The NCHA welcomes the draft NICE guideline on caring and supporting older people with learning disabilities. In particular, we welcome that NICE has clearly referred to "hearing and sight loss" throughout the guideline. This is a good contrast to the overly-broad term of "sensory loss", under which hearing loss and hearing care is too often marginalised or forgotten. To highlight the significance of hearing loss amongst older people with learning disabilities, and other vulnerable groups, it would be beneficial for NICE to ensure greater consistency in using "hearing and sight loss" throughout all of its guidance.	Thank you for your comment, and for your support for the guideline.

National Community Hearing Association	Full	78	6-14	The NICE draft guidance on adult hearing loss notes "The link between hearing loss and learning disability is well recognised", but acknowledged a lack of clarity about monitoring the hearing health of adults with learning disabilities. The same guideline also refers to NHS England advice that these adults should have their hearing tested annually. It would be helpful if NICE could ensure greater consistency across its guidance and shared learning across various Committees when drafting recommendations with respect to hearing loss and testing.	Thank you for your comment. Identification and monitoring of hearing loss is referenced in recommendations 1.5.6 and 1.5.13. We have added reference to hearing tests as part of regular health checks in recommendation 1.5.16.
National Development Team for Inclusion	short	general	general	Within PHE the focus is very much on reducing the prevalence and incidence of dementia https://www.gov.uk/government/publications/health-matters-midlife-approaches-to-reduce-dementia-risk/health-matters-midlife-approaches-to-reduce-dementia-risk However there is nothing in here about this. This guidance only addresses what to do once someone has been diagnosed. Give that people with learning disabilities have a higher risk of getting dementia it would seem a good idea to think about what can be done to reduce this risk.	Thank you for your comment. Disease prevention was outside the scope of the guideline. However, the guideline does make reference to supporting healthy ageing more generally. Please note that there is a separate NICE guideline on Dementia, disability and frailty in later life – mid-life approaches to delay or prevent onset.
National Development Team for Inclusion	short	general	general	We do know that many older people don't have family members that they can rely on for support and there is a reality that as people age, family and friends also age, so may not be able to offer that support. In the worst case scenario someone with learning disabilities may not have any people in their 'unpaid' support network that they can rely on. What consideration has been given to those people, where much of the consultation looks to have these people involved in conversations about their care and support? Without the support of someone there will be people that will not be able to access the care and support that the guidance details.	Thank you for your comment. We have amended the language throughout the guideline to include 'advocates' as well as family members and carers to encourage practitioners to think more widely about who may be available to support older people with learning disabilities. We have also now specifically highlighted the issue of people who do not have close family members, friends of carers in recommendation 1.1.10.
National Development Team for Inclusion	short	general	general	There does not appear to be any mention of people who may have a different first language to English.	Thank you for your comment. We have included in recommendation 1.1.5 reference to language needs and recommended the use of an interpreter and the provision of written material in people's preferred language.
National Development Team for Inclusion	short	3	6	As well as challenges relating to their learning disability, older people with learning disabilities may reach older age in poorer health due to lifestyle issues they have not been supported with such as lack of exercise and obesity	Thank you for your comment. This has now been added to the context section.
National Development Team for Inclusion	short	8	9	Even if the person does have close family members they should still be asked who they want involved – there might be someone who isn't family that they would like involved and equally there may be family members they do not want involved.	Thank you for your comment, which the committee took on board. In the final version of the guideline, 1.1.10 recommends asking the person who they want to involve regardless of whether they have close family. The same recommendation also alerts practitioners to be aware that some people do not have close friends and family. For those who do not have close family members, friends or carers, or there may be family members who the person do not want involved, the committee ensured that people with learning disabilities have access to advocacy services (1.1.5, 1.1.11, 1.2.5). Many of our recommendations included advocates as one of the key members of

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					the person’s support network in decision making, accessing services and care planning.
National Development Team for Inclusion	short	11	1	Can we recognise the importance of mutually positive relationships and opportunities for older people (with learning disabilities) to contribute in their community or through these groups?	Thank you for your comment. The committee agrees with you but they feel that the message is already implicit in recommendation 1.2.11 so no changes have been made.
National Development Team for Inclusion	short	14	25	If the person does not have a lasting power of attorney then this should be discussed while the person still has capacity	Thank you for your comment. We have amended recommendation 1.4.7 making reference to lasting power of attorney.
National Development Team for Inclusion	Short	16	20-18	Add changes to skin condition such as itchy or fragile skin. Also varicose veins (these can also cause itching)	Thank you for your suggestion, this has been added to the recommendation.
National Development Team for Inclusion	Short	17	1	Explore the use of summary care records as a way of sharing information. With their consent (or a best interests decision) extra information can be added. This might relate to reasonable adjustments that they need or it might be about end of life wishes for example.	Thank you for your suggestion. Having discussed it at length the committee decided not to recommend summary care records because in practice not everyone automatically or by default has access to one. They also felt that in the interests of future proofing the guideline it would be best not to introduce the concept.
National Development Team for Inclusion	Short	17	20 onwards	We feel there should be more emphasis on someone having an annual health check, as these can be an essential aspect of managing the health of people with learning disabilities. If the person has an annual health check they should also have a health action plan. This is vital in ensuring that relevant health needs are met and that medication is reviewed.	Thank you for your comment. The guideline committee have taken on board your comment – and those of other stakeholders who argued for a greater emphasis on annual health checks. After long discussions and further consideration of the economic analysis, as well as equalities issues relating to accessing health checks, the committee agreed to strengthen the reference to annual health checks by revising 1.5.12 to recommend ‘offering annual health checks to older people with learning disabilities’. However in light of the points you make, the committee also emphasised the fundamental importance of ensuring annual health checks are followed up with referral to specialist services – the health check in itself not being sufficient. To further strengthen the recommendation they also recommended that any actions identified in the health check be recorded in the person’s health action plan.
National Development Team for Inclusion	Short	18	21	Should this not also apply to other screening programmes, such as bowel screening?	Thank you for your comment. The list in this recommendation is based on the evidence reviewed by the committee. Of course bowel screening is also important but this list is only intended to provide examples.
National Development Team for Inclusion	Short	22	18	For people with Down Syndrome, this discussion may need to be had in their 30s	Thank you for your suggestion. The committee felt that it was suffice to say ‘at an early stage’ in this recommendation, not least because it is hard – and unhelpful – to be specific about the age at which any discussion or assessment should take place because it will vary for everyone.
National Development Team for Inclusion	Short	26	9	Add recognition of pain and discomfort	Thank you for your suggestion. We’ve added ‘recognition of pain and discomfort’ to the recommendation.
National Development Team for Inclusion	short	33	4 and 9	Advance care planning not advanced care planing.	Thank you for highlighting this typo, which has been corrected in the final guideline.
NHS England	Short	3	7	Does this include people with a learning disability who develop age related health conditions prematurely?	Thank you for your comment. The guideline does cover issues relating to early development of age-related conditions, and this is outlined in the context section under ‘The purpose of this guideline’.

NHS England	Short	4	9	*…the person is moved inappropriately* – suggest adding and often multiple times	Thank you for your comment. We have amended this section as you suggest.
NHS England	Short	5	1-3	This is welcome comment but is not reflected in title of guidance	Thank you for highlighting this. In light of yours and other stakeholder comments, the committee agreed to change the title of the guideline to more accurately reflect the focus of the recommendations. The title of the final guideline will be 'Care and support of people growing older with learning disabilities'.
NHS England	Short	10	19	Comment: services should be mindful of the person's experience of loss and multiple losses (e.g. health, carers, home)	Thank you for your comment. The committee believes the point is adequately covered in recommendations about future planning (e.g. that it should include planning for unexpected changes or emergencies) and also in the recommendations about planning for future housing needs and for support during end of life care.
NHS England	Short	12	9	Comment: the common poor practice of diagnostic overshadowing needs to be specifically mentioned	Thank you for your comment. We have amended recommendation 1.3.4 to highlight the issue of 'diagnostic overshadowing' and added a definition in the terms used, to which there a direct link from recommendation 1.3.4.
NHS England	Short	16	28	Suggest adding – bereavement & experience of loss (multiple losses)	Thank you for your comment. Bereavement issues are addressed in recommendation 1.4.4 so no changes have been made in light of your comment.
NHS England	Short	17	General	Pleased to see mention of the need to proactively screen for health conditions within this population and glad to see that Annual Health Checks are mentioned. However, it is disappointing that the 'cost analysis report' that you conducted did not find Annual Health Checks were cost effective for older people with a learning disability. These checks are more than a means of identifying health conditions alone but are also a means supporting primary care and secondary care services to make reasonable adjustments for people. Whilst your cost analysis methodology was sound it would be beneficial to consider that the Health Check covers a wider population than those that are older and note that many conditions such as diabetes have an early onset in the population of people with a learning disability than the general population. The annual health check as a proactive screening process increases detection of health conditions earlier in life and with earlier interventions can reduce the impact of these health conditions in older age. NHS England has increased investment in these checks with a raise in payment this year from £116 to £140 per check and have introduced a national template to improve quality and consistency of them in practice. Requirement for payment is a Health Check and provision of a Health Check Action Plan The national template builds on evidence of salient health conditions for people with a learning disability and through the 3 main GP practice clinical systems is now available in 80% of GP practices. The template identifies health needs and checks actions to address, but also includes section on consent to share information with other health services (e.g. Summary Care Record with additional	Thank you for your comment and all the information provided. The guideline committee have taken on board your comment – and those of other stakeholders who argued for a greater emphasis on annual health checks. After long discussions and further consideration of the economic analysis, as well as equalities issues relating to accessing health checks, the committee agreed to strengthen the reference to annual health checks by revising 1.5.12 to recommend 'offering annual health checks to older people with learning disabilities'. However in light of the points you make, the committee also emphasised the fundamental importance of ensuring annual health checks are followed up with referral to specialist services – the health check in itself not being sufficient. To further strengthen the recommendation they also recommended that any actions identified in the health check be recorded in the person's health action plan.

				information) and auto populates a Health Check Action Plan for patient to take away. We are working on a Reasonable Adjustment Flagging system with NHS Digital and the Check will provide an opportunity to create these for individuals. The Annual Health Check provides data that is interrogated via GPES to inform CCGs, Regions and National programmes to address health inequalities and variations. NHS England is committed to increasing the quality and uptake of the Health Checks. Annual Health Checks are a priority within the CCG Improvement & Assessment Framework (IAF). For the Learning Disability Programme within NHS England we have set an ambition that by March 2020 75% of people on GP Learning disability registers will have had an AHC. In the coming months we will be working on quality audit of checks and developing an Education programme for GP practices that we are looking to introduce into the Annual Health Check DES. If you would like more information on any of the above then please contact It would be appreciated if you could consider the additional benefits of Annual Health Checks in your guidance and if possible promote their uptake in stronger terms than you have already done.	
NHS England	Short	20	12	Good to see Oral health mentioned as an important aspect of health but would suggest equally strong focus on vision	Thank you for your comment. The evidence on which this recommendation was based was specifically related to dental services and oral health. The committee nevertheless agreed to also make reference to informing people about, and helping them to access, sight tests.
NHS England	Short	23	7	NHS England has recently produced guidance on Delivering end of life care for people with a learning disability that may be helpful https://www.england.nhs.uk/wp-content/uploads/2017/08/delivering-end-of-life-care-for-people-with-learning-disability.pdf	Thank you for this information, which we will pass to our endorsement team.
NHS England	Short	24	2	Suggest adding – something about more intense collaborative person centred options including PBS or Integrated Personal Commissioning, perhaps	Thank you for your comment. This is addressed in the revised recommendation 1.3.1 and 1.6.1 with a strong person-centred emphasis.
Plymouth Hospitals NHS Foundation Trust	short	17	2	It's getting increasing difficult to find allocated lead practitioners to this type of much needed input , the modernising of LD community teams/services has meant that in many areas people get	Thank you for your comment. The committee recognised the issues you raised. Unfortunately service organisation is not within the scope of this guideline.

				discharged after a period of care be it health or social care. People with LD and additional health needs as they get older (especially physical health needs) are no longer kept on and cased managed. I think this recommendation needs to be more specific about who should be responsible to do this and that it may be until EOL rather than a set period of care for example a newly diagnosed condition.	The recommendations on annual health checks (1.5.12) highlighted the need for follow-up by prompt referral to specialist services when necessary. We do anticipate that the recommendation will lead to positive changes in practice.
Plymouth Hospitals NHS Foundation Trust	short	20	17	This is a valid recommendation however it may need re wording to *Hospitals should find out if the person would benefit from* , rather than *should* as in our experience as a LD acute liaison service most people don't need or take up this opportunity.	Thank you for your comment. We have revised this recommendation to address this point (1.5.26).
Plymouth Hospitals NHS Foundation Trust	short	22	8	This in practice should happen however again due to the modernisation of LD community teams, new roles being developed with no new moneys and the transformation agenda (focus and priority given to a particular group of people with LD) it may be becoming more challenging to find nurse/practitioners whose role it is to pick up such work/cases on discharge from hospital and in a timely way. For example if someone is discharged on a Thursday who has said they can cope with their new diagnosis or medications but there is a suspicion that they may not and then e a referral is made on a Wednesday to community teams for a follow up welfare call it would not go to community MDT for review until the next week. By then it's a bit late for a follow up welfare call to see how the older person is getting on. Again due to referral processes and the time this takes it may be difficult to get the community teams involved in discharge planning unless they are already on someone's case load. It may be this is just an issue in some areas but I do think this recommendation needs to give more onus to who and how this can be achieved in an effective and timely manner.	Thank you for highlighting this issue. The committee did not review specific evidence about exactly how 'working together' can be achieved. It will vary across the country so it is assumed that in each area, practitioners will develop their own solutions for implementation. Also, for information, please note that the issues you raise are covered by another NICE guideline, due to be published on March 28th 2018. The guideline is entitled, Learning disabilities and behaviour that challenges: service design and delivery.
Public Health England	Short	General	General	This guidance assumes the individuals concerned generally have a degree of agency and interested family who will look out for them. Public Health England (PHE) agrees that for individuals with these advantages, their views and those of their families should carry weight. However many lack agency and, particularly as they get older, many also lack family support. The result is that there is a gap about the question of who will ensure that a person's best interests are looked after. Without some overarching support, those not able to independently take care of themselves will not be able to use the types of provision discussed. The language throughout should indicate the need to ensure similar considerations are attended to, if necessary by advocates, for people with learning disabilities with little capacity to express specific preferences and no involved family or friends.	Thank you for your comment, which the Guideline Committee discussed at length. Committee members did feel that this issue had been addressed, at least to some extent, in draft recommendation 1.1.9 which refers to key members of people's 'support networks' (which is defined in 'terms used' and which is clearly not limited to family members) and in 1.1.10 which recommends asking people who they wish to involve if they do not have family members. However the committee agreed that more could be done to address this issue and made a number of changes. First, they added a recommendation in the overarching principles to make practitioners aware that some people do not have close family members, friends or carers to participate in the planning or provision of support. Second, they adapted a recommendation from another NICE guideline, which states that independent advocacy should be offered wherever it is wanted or needed, in line with the Care Act 2014, the Mental Capacity Act 2005 and the Mental Health Act 2007. Finally, the Guideline Committee also agreed to review all the draft recommendations to ensure that – wherever appropriate – reference is made to 'family, friends, carers and advocates'. We hope that this addresses your concern.
Public Health England	Short	17	26	The references to learning disability annual health checks read as though these are only screening events. PHE consider them to be an essential reasonable adjustment in the provision of primary medical care to people with learning disabilities. A key product of the checks is the Health Action Plan (HAP). The HAP should be an essential requirement for ensuring that relevant health needs are considered daily by carers looking after people with learning	The guideline committee have taken on board your comment – and those of other stakeholders who argued for a greater emphasis on annual health checks. After long discussions and further consideration of the economic analysis, as well as equalities issues relating to accessing health checks, the committee agreed to strengthen the reference to annual health checks by revising 1.5.12 to recommend 'offering annual health checks to older people with

				disabilities. HAPs are more important when people are in residential settings as opposed to living with families, as they do not have the sole attention of their carers and there will be a degree of turnover in terms of paid carers. If people with learning disabilities do not have an annual (or regular periodic) health check, the HAP cannot be kept up-to-date. Annual health checks are a major element of NHS England's strategy for ensuring good primary care is provided for this group who are not, or not fully able to ensure their own primary care needs are met (https://www.england.nhs.uk/learning-disabilities/improving-health/annual-health-checks/). This is reflected in the fact that coverage of health checks is one of the three items included in the Clinical Commissioning Group Improvement and Assessment Framework (see Technical Annex, 2017/18, https://www.england.nhs.uk/wp-content/uploads/2017/11/ccg-technical-annex-2017-18.pdf Item 124b - Proportion of people with a learning disability on the general practice register receiving an annual health check). The learning disability health check also provides a key opportunity to ensure that important information about the care needs is recorded in the patients Summary Care Record. Dementia is known to be more prevalent in people with learning disabilities. One problem in diagnosing dementia in people with learning disabilities is that the clinician needs to know what the normal level of cognitive capacity was in adult life. Health Checks are a way that general practitioners (GPs) can keep track of this. The Royal College of General Practitioners' Toolkit (http://www.rcgp.org.uk/clinical-and-research/toolkits/health-check-toolkit.aspx) also identifies seven common syndromic conditions causing learning disabilities where specific regular medical checks are appropriate; the Annual Check provides the opportunity for these.	learning disabilities'. However in light of the points you make, the committee also emphasised the fundamental importance of ensuring annual health checks are followed up with referral to specialist services – the health check in itself not being sufficient. To further strengthen the recommendation they also recommended that any actions identified in the health check be recorded in the person's health action plan.
Public Health England	Short	18	11	The annual health check should include raising awareness of healthy lifestyles, where appropriate, which have an impact on dementia risk reduction such as reducing smoking and alcohol, eating a healthy diet. The strapline 'What's good for your heart is good for your brain': could be used by health professionals during a health check to highlight factors that increase the chances of developing vascular disease also increase the chance of developing dementia.	Thank you for your comments. We are aware of the importance of advice on healthy lifestyles. .We have made recommendations on how to help people keep well as they grow older (see recommendation 1.5.17 in the final guideline).
Public Health England	Short	22	16	In relation to dementia, this guidance focuses on the care and support people need once they have dementia. PHE promotes healthy lifestyles that can reduce the risk of dementia. PHE recommend including something about healthy lifestyle choices for people with learning disabilities, i.e. promoting healthy lifestyles linked to dementia risk reduction for people with early stages of dementia, their families and carers. 'What's good for your heart is good for your brain': factors that increase the chances	Thank you for your comment. This guideline focuses on care and support, disease prevention is not within scope. However the committee felt that within the confines of the guideline scope, reducing or delaying the need for care and support and promoting independence had already been well covered by the recommendations. For example, there are a number of recommendations focussed on living healthy lifestyles (1.2.12, 1.2.13, 1.3.5 in the draft guideline) and in the final guideline

				of developing vascular disease also increase the chance of developing dementia.	the committee agreed to emphasise the role of assessment in promoting independence.
Royal College of General Practitioners	Full	general	General	GPs are concerned with frailty and decline towards end of life and risk avoidance which can and has led to perhaps the wrong decisions. One example of this could be specifically thinking, about PEG insertion in those who are deemed by the SALT team as a choking risk. Homes are then almost pressed into this being done to their clients and they then lose the long individual attention during meals and can be a very long drawn out natural death. Few with capacity agree to this (in some GP's experience). When they finally reach the last few days they will trigger 'sepsis 'alerts if ringing 111 and will end up as a 999 admission. The new death reviews of all with LD (LeDeR) may show up areas of concern but the potential unintended consequence is a peaceful planned death may be harder to happen knowing all actions will be reviewed perhaps by those with no knowledge of the individual or their families. It is vital that the families can input into these reviews The above may be seen as being out of place with the whole document and certainly agree this service using group gets a raw deal in many ways and needs improving	Thank you for your comment. The recommendations on 'End of life care' aim to improve practice in this area. Please note there is a separate NICE quality statement on End of life care for adults.
Royal College of General Practitioners	Full	general	General	A thoughtful and comprehensive document, there is particular need to quantify the shape and size of this population and to get some measure of the problem and the cost implications of enlightened care.	Thank you for your comment. Recommendations 1.2.1 and 1.2.2 suggest that commissioners should understand the size and needs of this population.
Royal College of General Practitioners	Full	general	General	Areas and evidence not covered by the full guidance that should be considered 1. Falls and falls clinics 1. This longitudinal cohort study involved extensive baseline assessments, followed by a one-year follow-up on fall incidents. Falls occurred in 46% of the participants and the fall rate was 1.00 falls per person per year. The most important risk factors for falling in elderly persons with mild to moderate ID were (mild) severity of ID, (high) physical activity, (good) visuo-motor capacity, (good) attentional focus and (high) hyperactivity-impulsiveness, which together explained 56% of the fall risk. This pattern of risk factors identified suggests a complex interplay of personal and environmental factors in the aetiology of falls in elderly persons with ID. 1. Enkelaar L, Smulders E, van Schrojenstein Lantman-de Valk H, Weerdesteyn V, Geurts ACH. Prospective study on risk factors for falling in elderly persons with mild to moderate intellectual	Thank you for this important information. The review questions did not specifically seek evidence about falls prevention, which explains why there are no particular recommendations on the topic. However, the guideline does promote healthy living and healthy lifestyles in a number of recommendations and has a key focus on ensuring people remain as independent as possible for as long as possible. In addition, the recommendations on health checks and screening provide the opportunity to identify these various pre-disposing conditions leading to falls, and to take prompt actions. Your suggestions on improved flow of information across the health and care system, care, efficient care coordination, including issues on safeguarding, home adaptations, access to services, support for staff training and per-centred care are all good practice points to improve health and well-being of older people with intellectual disabilities. They are highlighted in our recommendations. We will also pass this information to our local practice collection team

				disabilities. Research in Developmental Disabilities. 2013 Nov 1;34(11):3754–65. 26 persons with ID and a fall history participated in the study. Process evaluation was conducted with evaluation forms and focus groups. Fifty interventions (0–8 per person) were prescribed. The (para)medical experts, clients, and caregivers described the falls clinic as useful. Advice for improvement included minor changes to clinic content. Logistics were the largest challenge for the falls clinic, for example organizing meetings, completing questionnaires prior to meetings, and ensuring that a personal caregiver accompanied the person with ID. Furthermore, the need for a screening tool to determine whether a person would benefit from the falls clinic was reported. In conclusion, the falls clinic for persons with ID was considered feasible and useful Smulders E, Enkelaar L, Schoon Y, Geurts AC, van Schrojenstein Lantman-de Valk H, Weerdesteyn V. Falls prevention in persons with intellectual disabilities: Development, implementation, and process evaluation of a tailored multifactorial fall risk assessment and intervention strategy. Research in Developmental Disabilities. 2013 Sep 1;34(9):2788–98. 2. Fraily Index A frailty index (FI) including 51 health-related deficits was used to measure frailty. Mean follow-up was 3.3 years. The Cox proportional hazards model was used to evaluate the independent effect of frailty on survival. The discriminative ability of the FI was measured using a receiver operating characteristic (ROC) curve. Results: Greater FI values were associated with greater risk of death, independent of sex, age, level of ID, and Down syndrome. There was a nonlinear increase in risk with increasing FI value. For example, mortality risk was 2.17 times as great (95% confidence interval (CI) = 0.95–4.95) for vulnerable individuals (FI 0.20–0.29) and 19.5 (95% CI = 9.13–41.8) times as great for moderately frail individuals (FI 0.40–0.49) as for relatively fit individuals (FI <0.20). The area under the ROC curve for 3-year survival was 0.78. Conclusion: Although the predictive validity of the FI should be further determined, it was strongly associated with 3-year mortality. Care providers working with people with ID should be able to recognize frail clients and act in an early stage to stop or prevent further decline. 1. Schoufour JD, Mitnitski A, Rockwood K, Evenhuis HM, Echteld MA. Predicting 3-Year Survival in Older People with Intellectual Disabilities Using a Frailty Index. Journal of the American Geriatrics Society. 2015;63(3):531–6. 3. Anticholingeric Drug Burden A modified Anticholinergic Cognitive Burden (ACB) scale score was calculated for a representative cohort of 736 people over 40 years old with intellectual disabilities, and associations with demographic and clinical factors assessed. Age over 65 years was associated with higher exposure (ACB 1–4 odds ratio (OR) = 3.28, 95% CI	

				1.49–7.28, ACB 5+ OR = 3.08, 95% CI 1.20–7.63), as was a mental health condition (ACB 1–4 OR = 9.79, 95% CI 5.63–17.02, ACB 5+ OR = 23.74, 95% CI 12.29–45.83). Daytime drowsiness was associated with higher ACB (*P*<0.001) and chronic constipation reported more frequently (26.6% ACB 5+ *v.* 7.5% ACB 0, *P*<0.001). 1. O'Dwyer M, Maidment ID, Bennett K, Peklar J, Mulryan N, McCallion P, et al. Association of anticholinergic burden with adverse effects in older people with intellectual disabilities: an observational cross-sectional study. Br J Psychiatry [Internet]. 2016 Sep 22; Available from: http://bjp.rcpsych.org/content/early/2016/09/09/bjp.bp.115.173971.abstract 4. Cessation and Deintensification of psychotropic medication See the NHS England STOMP programme https://www.england.nhs.uk/learning-disabilities/improving-health/stomp/ 5. Enhanced summary care records (SCR) when a patient consents to including additional information in their SCR, the GP can add it simply by changing the consent status on the clinical system. This means more information will be available to health and care staff viewing the SCR. It will then be automatically updated when the GP record is updated. This is a quick, cost-effective way to: • improve the flow of information across the health and care system • increase safety and efficiency • improve care • respond to particular challenges such as winter pressures. It's particularly useful for people with complex or long term conditions, or patients reaching end of life.	
Royal College of General Practitioners	Full	6	132-134	Specific age should be considered. Most research in learning disabilities defines old age as 50 years and older as there is reduced life expectancy. This is particularly important for advance care planning for people with Down's syndrome	Thank you for your comment. The work to develop the guideline scope – which included a stakeholder consultation - gave support to the approach of not using a specific age cut off to define 'older'. This is in recognition that adults with learning disabilities typically experience age-related difficulties at a younger age than the general population, and that the onset of age-related difficulties will vary from person to person. The Guideline Committee considered this issue again following consultation. Given the considerations above, the Committee retained their original position. The title of the guideline has been amended to reflect the fact that the focus of the guideline is the process of ageing, rather than 'older age' per se.
Royal College of General Practitioners	Full	20	523	The patient's clinical records should include alerts particularly around reason adjustments to add communication and continuity of care. The use of enhanced summary care records should be encouraged	Thank you for your comment. We have amended the recommendation to make clear that reasonable adjustments should be recorded in the person's care records, and communicated at the point of referral. However the committee did not agree to citing summary care records because they are not available widely and risk 'outdating' the guideline if a new term is rolled out. Instead they refer more generally to health action plans.

Royal College of General Practitioners	Full	24	645	Death and place of death needs to be talked about earlier so advanced care planning is potentially successful	Thank you for your comment. The wording of this recommendation has been amended to include the word 'timely' to reflect that end of life care should be considered at an early stage.
Royal College of General Practitioners	Full	26	689	A considerable proportion of deaths occur in institutional care. Bereavement services are needed for the paid staff and other residents	Thank you for your comment. Bereavement services for staff are outside the scope of the guideline. Recommendation 1.6.12 refers to support for friends, which would include other residents.
Royal College of General Practitioners	Short	General	1.4.5, 1.4.7, 1.4.11 and 1.6.4	Concerning "plans" that are put in place by healthcare professionals a specific review period is advocated (e.g. once a year, 6 months). Clinical practise would suggest that reviews are most effectively and efficiently done when prompted by a change in the person's need or circumstance. This is also advocated. The automatic specific review periods which are not based on evidence should be removed due to the increased work load placed upon healthcare practitioners without proven benefit.	Thank you for highlighting these review periods, which the Committee discussed. Their conclusions are listed here: Draft recommendation 1.4.5 – this doesn't actually include a specific review period. Draft recommendation 1.4.7 – this recommends that EOLC decisions (including place of death) should be reviewed 'at least once a year'. The review period was based on committee consensus and the group remained in agreement that this is achievable. In particular, they highlighted that the health action plans are reviewed annually and there should be no problem in including end of life care discussions in this process. Draft recommendation 1.4.11 – this recommends that the housing needs of people supported at home are reviewed at least once a year. This was also based on committee consensus and on discussing this further, the group wished to retain the 1-year review period. They emphasised that the review would not be the (sole) responsibility of health care professionals but also responsibility of other practitioners in social care and housing. The committee pointed out that it is good practice to regularly review people's changing needs to ensure they remain as independent as possible for as long as possible. In this context they believe the recommendation reflects good practice and is achievable. Draft recommendation 1.6.4 – this recommends asking people who they wish to involve in discussions about their end of life plan and states that this should be done every 6 months or more if they're approaching the end of life. The committee did not intend for this responsibility to fall on general practitioners alone. Considering the possible fluctuating mental capacity or difficulties in communicating among this population, the committee believed it was very important to retain the recommendation, to ensure the discussion is conducted and regularly reviewed.
Royal College of General Practitioners	Short	General	1.2.6	Telehealth - This has been shown to be of no use so why promote it in this group?	Thank you for your comment. This recommendation is based on a small amount of evidence which was supportive of tele-monitoring and having discussed the evidence the committee agreed a weaker, 'consider' recommendation, which is reflected in the wording. However in discussing your comment they agreed to make it clearer in the recommendation that neither telehealth nor telecare should be used in place of support provided by a person.
Royal College of General Practitioners	Short	17/18	1.5.13	The guidance suggests that this group of patients be asked about and monitored for symptoms of blood pressure, cholesterol, diabetes and osteoporosis. These conditions are asymptomatic (except for a small proportion of diabetics).	Thank you for your comment, which the committee considered. On balance they decided to keep the items listed because symptoms and conditions frequently go unnoticed in this population that they wanted to encourage the broadest awareness and consideration of possible health issues.
Royal College of General Practitioners	Short	17	1.5.9	Primary healthcare teams are being asked to identify a clinical champion. General practitioners are generalists. There is no evidence of benefit that a primary healthcare team should have a	Thank you for your comment. It was not a 'clinical champion' as such that was recommended by the committee. Instead it was a member of staff who would model good practice and share knowledge about

				clinical champion. It would be possible for all medical illnesses to advocate that a clinical champion be identified within primary care which has a limited number of staff. Identifying a clinical champion would put an additional burden on the primary healthcare team which has limited resources. Primary care organisations may however have a safeguarding lead which would include vulnerable adults	working with older people with learning disabilities. They considered the resource implications and agreed that any additional cost would be balanced with the champions' contribution to ensuring appropriate use of health and care services. The committee did not make any changes in light of your comment.
Royal College of Nursing	All	Question	2	*Question 2*: Other challenges both resources and financially will be for housing provision and in particular adaption. Overall, most local authorities have reduced their budgets for adaptive work. We already see long waiting lists for people waiting for any adaptation to their homes whatever their situation.	Thank you for your comment. The Guideline Committee considered carefully the resource impact of the recommendations. The recommendations are considered to be aspirational but achievable. The view of the committee was that resources spent on enabling people to remain in their own homes could lead to savings in terms of avoiding more costly residential placements.
Royal College of Nursing	General	General	General	The Royal College of Nursing (RCN) welcomes proposals to develop guidelines for the care and support of older people with learning disabilities. The RCN invited members who work with older people and people with learning disabilities to review this document on its behalf. The comments below reflect the views of our reviewers.	Thank you for comment, and your support the guideline.
Royal College of Nursing	General	General	General	There are several parts of the guidelines particularly in the overarching principles, that should be easy to implement and in reality they only reflect the type of individualised care that all people should receive. As this guidance does really focus on a person centred approach we do not feel there is any one area that is more important than any other.	Thank you for your comment.
Royal College of Nursing	Short	9	6	The suggestion that GP practices should maintain a register of people with learning disabilities may be difficult to implement as the requirement is not currently in place. GP practices are required to maintain many different lists and the recent Contract change has resulted in the need for Frailty identification as well. Whether GP practices could use their Frailty lists for the dual purpose of identifying people living with learning disabilities is a possibility as many people with learning disabilities do also live with Frailty. This, however, needs to be explored.	Thank you for your suggestion. The committee considered your point but felt it would be inappropriate to link this recommendation to the frailty register, especially since primary care *should* maintain a learning disability register. If they don't already then this recommendation will encourage them to do so and indeed, this would be in line with the Quality Outcomes Framework.
Royal College of Psychiatrists	Full	28	759	Although it is understandable to prevent exclusion/discrimination that a specific age limit is not used to define older people because adults with learning disabilities typically experience age-related difficulties at different ages, and at a younger age than the general population, this can also be a significant hurdle in this population to ensure equity and access. How would primary care and other commissioners identify the relevant cohort covered by this guideline if they can't specify who older adults with learning disabilities are? How do you audit that the guideline is being implemented effectively without some clear definitions or general road map? In most publications, including those from BILD, the age 60 is highlighted as general guide for older adults with learning disability. However, age can be specified as irrelevant with conditions such as Dementia which can manifest in the 30's and 40's in patients with a learning disability.	Thank you for your comment. The work to develop the guideline scope – which included a stakeholder consultation - gave support to the approach of not using a specific age cut off to define 'older'. This is in recognition that adults with learning disabilities typically experience age-related difficulties at a younger age than the general population, and that the onset of age-related difficulties will vary from person to person. The Guideline Committee considered this issue again following consultation. Given the considerations above, the Committee retained their original position. This would not preclude local areas from selecting an age cut off point for the purposes of local audit, or to conduct audit based on age-related conditions within the learning disability population. The title of the guideline has been amended to reflect the fact that the focus of the guideline is the process of ageing, rather than 'older age' per se.
Royal College of Psychiatrists	Short	10	26 – 30	There is limited guidance on how the interface between mainstream Old age psychiatry and Intellectual disability services should be managed and specifically whether one service is better equipped to take the lead in the acre of older adults including those with specific	Thank you for your comment. Although you make a good point, the committee were unable to develop specific recommendations to address this issue due to lack of relevant evidence. In addition, it is important to highlight that it is not within the remit of this guideline to

				conditions such as Dementia. This has a lot of training and resource implications which are largely ignored in this guidance.	recommend how services should be configured (this would be a service model guideline), or how services should be funded. However, In the case of budget constraint, using existing resources differently may have to be considered.
SeeAbility	Short	General	general	SeeAbility acts to improve eye care for people with learning disabilities as they are a group that experiences an exceptionally high level of sight problems from birth to older age. We also provide care and support services for people with learning disabilities, autism and other complex needs, and a number of people we support directly are of older age. Adults with learning disabilities are 10 times more likely to have serious sight problems than the general population (see research commissioned by RNIB and SeeAbility from Improving Health and Lives https://www.seeability.org/Handlers/Download.ashx?IDMF=511dbb2c-08fb-40e8-b568-a2ed38a4ea13). This report shows that as sight problems increase with age, as people with learning disabilities get older the prevalence of visual impairment or significant refractive error grows (an estimated 14% of people with learning disabilities over 50 are sight impaired or severely sight impaired, and over 56% have refractive error), as will the risk of age related macular degeneration, cataracts and other eye health conditions. People with learning disabilities may be at greater risk of accidents and falls, or need more costly packages of support from health and social care due to avoidable sight loss. SeeAbility very much welcomes the draft guideline for highlighting actions that can be taken to support older people with learning disabilities, and in particular for giving profile to the risk of sensory impairments in people with learning disabilities and actions that health professionals can take. In particular the focus on accessible information is helpful and we would be delighted if NICE, when publishing the guideline, could include signposted information to SeeAbility's easy read information, such as information on having a sight test, and eye conditions that are likely to present in people with learning disabilities, such as cataract. https://www.seeability.org/looking-after-your-eyes It is very important to note that someone with a learning disability may not be able to effectively communicate visual problems or symptoms or visual impairment can often be misattributed to someone having a learning disability, and overlooked. Therefore access to sight tests is extremely important in understanding if someone has a problem with their vision. We have supported people to access eye care: surgery for cataracts, and refractive error correction for age related presbyopia – in many cases the individuals were thought to have become 'withdrawn', or 'challenging' or were even having tests for early onset dementia, before their vision status had been established.	Thank you for your comment. We have amended recommendation 1.5.16 to make reference to informing people about, and helping them to access, sight tests. Recommendation 1.3.4 also makes reference to diagnostic overshadowing, with examples provided in the 'terms used' section. In terms of the material you reference, we will pass this to our endorsement team.
SeeAbility	Short		1.2.7	While we welcome the statement in 1.2.7 that commissioners should seek to identify where there are gaps in community optometry and dental services for older people with learning disabilities and seek to	Thank you for your comment and the information you provide, which the committee discussed. They agreed to remove the specific

				address those gaps, it is actually the responsibility of NHS England to provide the funding and framework for the operation of primary optometric care and not clinical commissioning groups as stated. Unfortunately the NHS England sight testing contract has overlooked the needs of those with learning disabilities, by providing no incentive to provide longer, reasonable adjusted appointments in practices or day centres. Any optometric appointment in these circumstances pays £21.31, the same as any routine 'high street' sight test. In a few local areas, pathways have been developed for people with learning disabilities through commissioners prepared to pay to 'fill the gap' in the funding system, but this isn't a solution to getting national coverage of services for people with learning disabilities. NICE should either add into 1.2.7 "address those gaps *with NHS England*" rather than seek to encourage local commissioners to address a system they have no commissioning responsibility for, or more preferably explicitly state "*that NHS England should seek to address any gaps in community optometry services through its role as primary optometry commissioning body.'.*	reference to 'clinical commissioning groups' and instead refer more generally to 'Commissioners' in the recommendation.
SeeAbility	Short		1.5.6	We very much welcome the statement in paragraph 1.5.6 to consider training for people and their family members and carers in recognising and managing age- related conditions such as sight loss. However, we question who this statement is directed to – it seems to be healthcare practitioners – but it should be for commissioners to commission this training so healthcare practitioners can operationalise it.	Thank you for your comment. The recommendation has been amended so that it is aimed at 'commissioners and providers'.
SeeAbility	Short		1.5.9	We also welcome the statement under 1.5.9 on identifying people with knowledge and skills within primary care teams, and this should include optometrists and dispensing opticians within primary eye care.	Thank you for your comment. The committee deliberately avoided making specific reference to the practitioner who could take on this role as it will vary in different teams. Therefore they decided not to make the change you suggested although please note that in other recommendations, specific reference to optometry services and sight loss have been made in response to your feedback.
SeeAbility	Short	General	general	Under health checks and screening, NICE emphasises the importance of being registered with a dentist (paragraph 1.5.15 and advice for dentists 1.5.22). There is no mention about asking about recent sight tests as well as ensuring commissioners ensure that people with learning disabilities can make the best use of their vision. **We feel there is is a very strong argument for this section to include more on this subject.** **We suggest** ***"Given the high risks of sight problems in people with learning disabilities ensure the person is accessing regular sight tests with a community optometrist and that support staff are aware of the risks and the need to support the person to make the best use of their sight. This includes ensuring the person has access to and is supported to wear the right spectacles, as well as access to onward treatment and surgery, and maintenance***	Thank you for your comment. We have amended recommendation 1.5.17 to make reference to informing people about, and helping them to access, sight tests. With regard to commissioning, recommendation 1.2.7 states that commissioners should identify gaps in community optometry services. In addition, 1.5.14 under 'health checks and screening' recommends that practitioners ask people about and monitor people for symptoms – with hearing loss and sight problems at the top of that list of examples, Finally, 1.5.6 recommends that training is commissioned for people and their families to help them recognise and manage age related conditions, again with hearing and sigh loss and the top of the list of examples, Hopefully this reassures you that the guideline does not assume that annual health checks are the only opportunity for identifying and managing sight loss problems.

				of treatment in the community. This may also include the need for vision rehabilitation services to support independence". Our reasons and evidence are as follows: • Given the risks of serious sight problems is much higher in this group, any problem with vision is much more likely to impact on independent living than dental problems. This can be a gradually developing need for refractive error correction (age related presbyopia, manifest hyperopia) or development of cataract or open angle glaucoma, or more urgent conditions may develop such as corneal ulcers, retinal detachment or acute glaucoma which need prompt treatment. If there is poor access to eye care then, subsequent visual impairment may compound pre-existing disability in some people with learning disabilities. Evidence of compounding issues: Evenhuis H M, Does visual impairment lead to additional disability in adults with intellectual disabilities? Journal of Intellectual Disability Research vo 53 No. 1 pp 19-28, 2009. • Nor should NICE rely on annual health checks as a roundabout way of ensuring vision is checked. The problem with 'health checks' is if interpreted as the GP annual health check, is that GPs do not undertake sight tests nor comprehensive eye examinations, and there is evidence that people are not being told about sight tests during the annual health check. There is also evidence that people may misunderstand what types of checks they are having on their sight – for example people who go to diabetic eye screening may think they are having a full sight test. Evidence of poor reference to vision in GP health checks: Codling, M. (2013), 'Eye Know': translating needs from annual health checks for people with learning disabilities to demand. British Journal of Learning Disabilities, 41: 45–50; Carey et al (2017). An evaluation of the effectiveness of annual health checks and quality of health care for adults with intellectual disability: an observational study using a primary care database. Population Health Research Institute. Health Services and Delivery Research Volume 5, Issue 25, • There is published evidence that awareness of the eye care needs of people with learning disabilities amongst staff in residential and day care services can be low, perpetuating problems in identification and management of sight problems in these environments. And as reporting of sight problems is often symptom led this puts people with communication difficulties at major risk of not getting the eye care they need. This includes support to continue wearing of their glasses.	

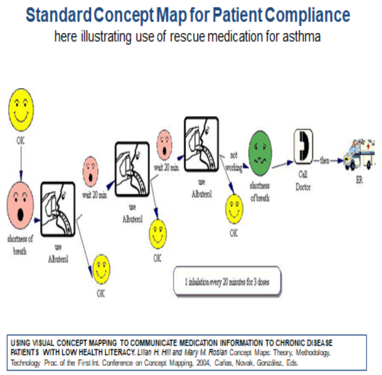
				Evidence of low awareness: Newsam, H., Walley, R. M. and McKie, K. (2010), Sensory Impairment in Adults With Intellectual Disabilities—An Exploration of the Awareness and Practices of Social Care Providers. Journal of Policy and Practice in Intellectual Disabilities, 7: 211–220; Leamon, S. et al (2014). Improving access to optometry services for people at risk of preventable sight loss: a qualitative study in five UK locations. J. Public Health (Oxf). 1–7. There is also a general lack of awareness by those brokering or commissioning services for older people with learning disabilities in respect of rehabilitation services for those with visual impairment, and the benefits these services provide in maintaining independence and daily living skills.	
SeeAbility	Short	General	general	As an addendum, we are surprised that there was very little in the supporting evidence section on research around access and facilitation to optometric checks amongst older adults with learning disabilities. There has been a number of studies including a longitudinal study of adults aged over 50 years of age in the Netherlands (see *Van Isterdael, 6220 institutionalised people with intellectual disability referred for visual assessment between 1993 and 2003: overview and trends, and Van Splunder et al. Prevalence of visual impairment in adults with intellectual disabilities in the Netherlands: cross sectional study, Li (2015) The challenges of providing eye care for adults with intellectual disabilities*). The latter in particular notes how improvements to deinstitutionalise people with learning disabilities have not been accompanied by improvements in primary eye care. As well as these international studies, a number of studies in the UK that have recommended targeted optometric examination of people with learning disabilities (eg. *Woodhouse et al, A. (2000), The prevalence of ocular defects and the provision of eye care in adults with learning disabilities living in the community; Starling, S et al (2006), 'Right to sight' Accessing eye care for adults who are learning disabled; Stanford and Shepherd (2001). A vicious circle: visual impairment in people with learning disabilities)*	Thank you for this information. These studies were identified by our systematic search but did not meet our criteria. Li (2015) – Excluded as age of population not specified. Starling et al. (2006), Excluded – as this is a prevalence study (not one of our included study types), also population involved people with disabilities of all ages Van Splunder (1993, 2003); Woodhouse et al (2000); Stanford and Shepherd (2001) - These 4 studies were published pre-2005, outside our 10-year search dates.
SeeAbility	Short	General	general	SeeAbility acts to improve eye care for people with learning disabilities as they are a group that experiences an exceptionally high level of sight problems from birth to older age. We also provide care and support services for people with learning disabilities, autism and other complex needs, and a number of people we support directly are of older age. Adults with learning disabilities are 10 times more likely to have serious sight problems than the general population (see research commissioned by RNIB and SeeAbility from Improving Health and Lives	Thank you for your comment. We have amended recommendation 1.5.16 to make reference to informing people about, and helping them to access, sight tests. Recommendation 1.3.4 also makes reference to diagnostic overshadowing, with examples provided in the 'terms used' section.

				https://www.seeability.org/Handlers/Download.ashx?IDMF=511dbb2c-08fb-40e8-b568-a2ed38a4ea13). This report shows that as sight problems increase with age, as people with learning disabilities get older the prevalence of visual impairment or significant refractive error grows (an estimated 14% of people with learning disabilities over 50 are sight impaired or severely sight impaired, and over 56% have refractive error), as will the risk of age related macular degeneration, cataracts and other eye health conditions. People with learning disabilities may be at greater risk of accidents and falls, or need more costly packages of support from health and social care due to avoidable sight loss. SeeAbility very much welcomes the draft guideline for highlighting actions that can be taken to support older people with learning disabilities, and in particular for giving profile to the risk of sensory impairments in people with learning disabilities and actions that health professionals can take. In particular the focus on accessible information is helpful and we would be delighted if NICE, when publishing the guideline, could include signposted information to SeeAbility's easy read information, such as information on having a sight test, and eye conditions that are likely to present in people with learning disabilities, such as cataract. https://www.seeability.org/looking-after-your-eyes It is very important to note that someone with a learning disability may not be able to effectively communicate visual problems or symptoms or visual impairment can often be misattributed to someone having a learning disability, and overlooked. Therefore access to sight tests is extremely important in understanding if someone has a problem with their vision. We have supported people to access eye care: surgery for cataracts, and refractive error correction for age related presbyopia – in many cases the individuals were thought to have become 'withdrawn', or 'challenging' or were even having tests for early onset dementia, before their vision status had been established.	
Sense	Full	General	General	Sense is a national disability charity that supports people with complex communication needs. Many of the people we support live with a loved one who is their primary carer. Over the course of wide ranging research undertaken over the last year, disabled people and their families told us about their concerns and anxieties for future care provision when they are no longer able to support their disabled family member or friend. We will be publishing a report on our research findings in January 2018, we will be able to share those findings in full, with NICE at that time. Given the research we have done, we welcome the development of this guidance, and hope it can promote improved practice and long-term person-centred planning for disabled people and their carers as they grow older. We are particularly pleased to see explicit reference to the Accessible Information Standard within the draft guidance. We were also pleased to see explicit reference to the fact that sensory impairment can be a barrier to accessing services (short version page 4).	Thank you for this information. No more evidence will be formally reviewed for this guideline. However, NICE takes account of the publication of new evidence when deciding whether to update the guideline in the future. With regard to the Accessible Information Standard, the wording 'must' indicates that this is a statutory duty. We make a number of recommendations regarding involving families and carers (see recommendations 1.1.9, 1.1.10. 1.1.12, 1.3.6, 1.4.1, 1.4.3, 1.4.6, 1.4.12, 1.4.13, 1.5.1, 1.5.5., 1.5.6,. 1.5.31, 1.5.33, 1.6.1, 1.6.6, 1.6.7, 1.6.10) and providing assessment and support for families and carers in their own right (see recommendations 1.2.3, 1.2.5, 1.3.7, 1.3.8, 1.3.9, 1.3.10, 1.5.37, 1.6.12). With regard to provision of information, this is covered in recommendation 1.1.6. This is an overarching recommendation, so would also apply to future planning.

				Our comments here focus on a range of technical and semantic issues within the guidance. However, there are several key principles that we believe should inform the guidance throughout: - It should be clear that the Accessible Information Standard is a legal duty, incumbent upon all providers of all publicly funded adult social care and health. - The role of carers and the needs of carers should be given consistent and equal consideration to people with care and support needs, in line with the spirit of, and guidance to, the Care Act 2014. - Key to addressing issues with future planning, is access to timely, appropriate and accessible information and advice (in line with the Care Act duties). Provision of statutory, universal information and advice should be seen as a key means to support families and disabled people to plan for the future. - The guidance should recommend that local authorities support disabled people, of all ages, and their families to plan for the future and to develop long-term contingency plans to ensure their future care and support needs are met. - Sensory impairment and communication needs present a barrier to accessing services for many older people with learning disabilities. Whilst prevalence of sensory impairments in people with learning disabilities are high, identification and understanding of these is low. These barriers can be overcome by the provision of appropriate information, screening and suitable care models.	With regard to future plans, this is covered by the recommendation in Section 1.4 on ‘Planning for the future’. Ensuring that people’s communication needs are met is covered by recommendation 1.1.5. Recognition and management of sensory impairment is covered in recommendations 1.5.6, 1.5.13 and 1.5.15.
Sense	Full	General	General	We are concerned that there is no reference to safeguarding in the draft guidance. We believe this must be addressed, and that the guidance must make reference to safeguarding protocols, policies and procedures. This could just be a reference to separate NICE guidance.	Thank you for your comment. We have strengthened the references to safeguarding in the guideline by: - including reference to safeguarding in the introduction, including stating that practitioners must follow local safeguarding procedures - adding in reference to recommendation 1.1.6 to providing people, and their families, carers and advocates with information about safeguarding procedures - adding in reference to recommendation 1.7.3 about training for staff.
Sense	Full	8	160-163	We believe that it would be useful if this section of the guidance on ‘reasonable adjustments’ gave some practical examples of what that may include. Necessary and reasonable adjustments should form part of a holistic, person-centred care plan which should reference the views of a person’s family, carers and other professionals involved in their care and support, including care workers, support workers and occupational therapists.	Thank you for your comment. The Guideline Committee discussed whether to give examples. The view of the Committee was that a list of examples may be interpreted as exhaustive, when in fact adjustments should be determined by the needs of the person. The phrase ‘person-centred reasonable adjustments’ has been added to this recommendation.
Sense	Full	8	171	This section makes reference to the Accessible Information Standard, the standard is a duty that providers must comply with, this section states that the duty applies to ‘practitioners’. The term practitioner should be replaced with provider. However, it is also the case that practitioners have a key role in ensuring that the standard is fully implemented. This should be referenced, but it should also be clear that the legal duty applies to providers.	Thank you for your comment. We have amended the recommendation to make clear that the duty applies to providers, but that practitioners have a key role in ensuring that the standard is fully implemented.

Sense	Full	9	204-208	This section on mental capacity and decision making should be strengthened, to make clear that clinicians should take a lead role on making best interest assessments and communicating their outcome. From our experience of providing social care to people who lack capacity, we are aware of examples where clinical professionals have deferred decision making and responsibility to non-clinical professionals and/or care workers.	Thank you for your comment. Recommendation 1.1.8 makes clear that health and social care practitioners must understand and consider the Mental Capacity Act 2005 when working with older people with learning disabilities. Following stakeholder comments, we have also added reference to the Mental Capacity Act to recommendation 1.7.3 on training. There is an additional NICE guideline in development on Decision making and mental capacity.
Sense	Full	12	281-284	This section should refer to the Green Light Toolkit, which was developed by the National Development Team for Inclusion (NDTi) which outlines effective protocols for commissioning mental health services for people with learning disabilities.	Thank you for your comment. We did not find any evidence for this toolkit specifically, and so are unable to make a specific recommendation about this although the issue is addressed in the NICE guideline on mental health problems in people with learning disabilities.
Sense	Full	14	331-333	We believe that this section should directly reference diagnostic overshadowing and provide practical examples of situations where a health condition not related to a learning disability has resulted in a presentation of behavioural changes. For example, a situation where impacted ear wax has led to a change in behaviour in a person with a learning disability.	Thank you for your comment. The recommendation has been amended to make specific reference to diagnostic overshadowing and a definition of the terms has been added to the 'terms used' to which the recommendation links directly.
Sense	Full	22	632-642	The list of training and information types for older people with learning disabilities being assessed for dementia and their families should include reference to sensory impairments. There is existing SCIE guidance on dementia and sensory support services which may act a useful reference point for NICE.	Thank you for your comment. Training in relation to hearing loss and sight problems is covered in recommendation 1.5.6.
Sense	Short	7	20	We are pleased to see reference to the Accessible Information Standard, however the document does not make clear that compliance with the standard is a legal duty on providers. This should be made explicitly clear, current wording suggests it is optional 'good practice'.	Thank you for your comment. The guideline is very clear that compliance with the Accessible Information Standard is a legal duty and this is reflected in the use of the term 'must in recommendation 1.1.5. In NICE guidelines, the use of 'must' signifies a statutory duty.
Sense	Short	13	9-12	This section makes reference to "planning for future" – which later in the guidance (section 1.4.5) is defined in terms of crisis planning and planning for life changing events. This is of course very important, but long-term planning should also account for aspirations, and not just for crisis response.	Thank you for your comment. Long-term planning is clearly addressed in recommendations 1.3.5, 1.4.1 and 1.4.6.
Sense	Short	13	19-22	In reference to support given to families and carers, the guidance cites signposting to support people after bereavement as an example of proactive practice. In our view, this does not constitute proactive practice, the focus should be on early intervention and supporting people to plan for the future. We believe that this section of the guidance should be strengthened, in reference to Care Act universal signposting duties, and changed to 'local authorities must establish a universal and accessible information and advice service to signpost people, their families and carers to care and support services. This service should focus on proactive future planning, and not on crisis response. This will support them to plan for their current and future care and support needs.'	Thank you for your comment. There is already a major focus in the guideline on helping families and carers to support the person, ensuring they have a breadth of training and information. Future planning is also covered in recommendations 1.4.5 to 1.4.7 where the emphasis is certainly on planning and putting things in place before problems or changes occur. In addition, the context section has been edited to refer to the important legislative context within which these recommendations should be implemented, including the Care Act 2014.
Sense	Short	14	27-30	In relation to the Deprivation of Liberty Safeguards (DoLS) the draft guidance should account for the proposed reform and reference the proposed Liberty Protection Safeguards. With particular reference to the change in focus from 'deprivation' to 'protection'. Where a person has been assessed to lack capacity, the care plan should focus on how a person's liberty can best be safeguarded and protected throughout the provision of care and support. This should be a key part of a holistic, person-centred care and support plan for people who lack capacity.	Thank you for your comment. The committee acknowledged the evolving policy context but felt that the bullet point in 1.4.7 reflected the issues they were aiming to highlight and did not require editing at this stage. When this guideline is reviewed to see if there is a need for update, then any legislative developments might be reflected in the wording along the lines you have suggested.

Sense	Short	15	4-26	The section on future housing needs should include reference to local authorities' responsibilities to facilitate and stimulate their local housing supply, particularly in relation to supported housing, accessible housing and the distribution of the Disabled Facilities Grant.	Thank you for your comment. We agree that housing supply is a pertinent policy issue. However, it is not within the scope of this guideline. We nevertheless anticipate that our recommendations will lead to positive changes in this respect.
Sense	Short	15	18-20	This section operates under the assumption that older learning disabled people's health and wellbeing will deteriorate, and that deterioration for a tenant in a supported living setting necessitates a move to residential care. We do not believe this to be the case, the guidance should include similar reference to people moving from residential care to supported living, as well as reference to the fact that deterioration in health and wellbeing should not necessitate a move to residential care. Indeed many community care models including supported living can provide outstanding care and support to people with very complex support needs.	Thank you for your comment. We have amended recommendations 1.4.11 to 1.4.13 to make this clearer. Please also note that recommendation 1.4.10 refers to enabling people to stay at home.
Sense	Short	17	1-19	This section should include reference to sharing information between health and social care practitioners; it currently refers only to information sharing between health practitioners. Sharing data between the NHS and local authorities requires a secure e-mail server on the part of the local authority, this should be referenced.	Thank you for your comment. We have amended recommendation 1.5.10 to be more inclusive by referring to 'relevant' practitioners.
Sense	Short	22	8-11	This section should reference the fact that some hospitals and trusts do not have a learning disability liaison nurse on their staff. The guidance should state that having a specialist liaison nurse is good practice, and also cover action to be taken in instances where there is no specialist liaison nurse.	Thank you for your comment. The committee discussed your point and they felt that the majority of hospitals and trusts do have learning disability liaison nurses so it is a reasonable to make in this recommendation.
Skills for Care	Easy read slides	Slide 12 - 14		We are concerned that this does not require people to pro-actively find a way of helping people plan ahead for a time when their existing carers (or care services) won't be able to meet their needs. Many families are providing care at home to older people and do not have a way of thinking about a time when their parents will be unable to provide that care or will die.	Thank you for your comment. Many of the recommendations are designed to encourage people to think about the future and they state that practitioners should be enabling these conversations and planning early. In particular recommendation 1.4.5 states that practitioners should work with the person to plan for their future, helping them to make decisions before a crisis point.
Skills for Care	Easy read slides	Slide 24		"Offer people the same health checks and **screening tests** as other older people. (Screening tests check for health problems even in people who feel well.) Ask people if they see a dentist. Ask if they know how to look after their teeth." We are concerned that this does not accurately reflect the need for reasonable adjustments to 'the same health checks'; it doesn't stress how individuals with a learning disability may not be aware of the impact of sight and hearing problems. This advice does not seem to be proactive enough – simply asking people if they see a dentist and know how to look after their teeth is not enough.	Thank you for highlighting this. On cross checking to the recommendations, the committee believes it is implied that screening and health checks are both promoted in this guideline – it may be that this did not clearly translate to the easy read slides and we will follow this up. There is an overarching recommendation (1.1.3) about reasonable adjustments, and a recommendation about supporting communication needs (1.1.5). Ensuring that people know the importance of, and how to access, hearing and sight tests has been added to recommendation 1.5.17.
The Dirac Foundation	Short	General	general	Could attention perhaps be given to the organized use of concept/mind maps with icons and/or Bliss symbolics for the reading impaired, and in particular the use of an eHealth linked IT system to quickly translate and present medical advice and instructions into such visual knowledge map forms?	Thank you for your comment. We have not made specific reference to these tools, as no specific supporting evidence was located in our review. However, the guideline is very clear that practitioners must support people's communication needs and preferences, that changing communication should be monitored and responded to and that practitioners should have the skills needed to communicate with people in whatever way they prefer.

				[1] Learning Disabilities and Brain Function: A Neuropsychological Approach, William H. Gaddes, Dorothy Edgell, Springer Science & Business Media, 2013; [2] 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 Proc. of the First Int. Conference on Concept Mapping, 2004, Cañas, Novak, González, Eds.; [3] http://www.blissymbolics.org/index.php/resources/59-planning-a-communication-language-and-literacy-program [4] Blissymbolics in dysphatic schoolchildren, Marjatta Jaroma Kuopio : University of Kuopio : Kuopio University Library [jakaja], 1992.  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 Proc. of the First Int. Conference on Concept Mapping, 2004, Cañas, Novak, González, Eds.	Thank you for the suggestions for additional references.Unfortunately these do not meet our review criteria. [1] Gaddes et al. (2013) This is a book, which was one of the types of literature we excluded for the evidence review. [2] Hill et al. (2004) This was published in 2004, which is out of our 10-year search criteria. [3] http://www.blissymbolics.org/index.php/resources/59-planning-a-communication-language-and-literacy-program. This is a commentary by one person on a website and not an empirical study suitable for our evidence review. [4] Jaroma (1992) – this is outside our 10-year search criteria.
The Downs Syndrome Association	Short	General	General	Whilst we welcome these guidelines and support all moves to improve the quality of healthcare for older people with a learning disability, we have significant concerns that the implementation of the guidelines may, in practice, be unrealistic – given what we encounter through our advocacy work with individuals and their families. For example, the fact that commissioners should make available respite care or day opportunities doesn't mean that the provision of these services will be sufficient to meet demand or	Thank you for your comment. NICE guidelines make recommendations about best practice, based on available evidence. They are not mandatory, but NICE undertakes a number of activities to support implementation and through liaison with national stakeholders. Where the recommendations are supported by law, this is indicated by recommendations that are worded as 'must'.

				accessible for individuals who need this support. It just means commissioners should provide 'some'. Guidelines would be much more useful if they were couched in terms of the user, through a rights based approached e.g. *"It is the right of every older person with a learning disability to be provided with….* We fear these guidelines are weak because they have little weight in law, in practice services may choose to implement what they see as guidance, rather than a requirement to do so.	
The Downs Syndrome Association	Short	3	2	We wish it be noted that increasing life expectancy for people with a learning disability is to be celebrated. This has been especially dramatic for people with Down's syndrome - median age at death increased from 25 years in 1983 to 49 years in 1999, Yang et al (2002) and in 2017, median life expectancy is 58, The LonDownS consortium (2017).	Thank you for your comment. The first 2 sentences of the Context section acknowledged the increased life expectancy of people with learning disabilities in recent years. NICE agrees with you wholeheartedly that this development is to be celebrated but the purpose of the context section is simply to provide an objective demographics, practice and policy background to the recommendations.
The Downs Syndrome Association	Short	3	5	We highlight that, while there is a higher prevalence of certain health conditions in people with Down's syndrome (e.g. hypothyroid, sensory impairments, early onset dementia), lack of awareness and insufficient training for health and social care staff can often mean people with Down's syndrome are at risk of experiencing diagnostic overshadowing, meaning there is a tendency for clinicians to attribute symptoms or behaviours of a person with a learning disability to their underlying cognitive deficits and hence to under-diagnose the presence of another, treatable, condition. We would add that issues of undiagnosed or untreated depression is much higher amongst people with a learning disability. https://www.mencap.org.uk/learning-disability-explained/research-and-statistics/health-research-and-statistics/mental-health We would include attention to ineffective strategies to manage pain, see studies by Diana Kerr, University of Edinburgh. https://www.jrf.org.uk/report/pain-management-older-people-learning-difficulties-and-dementia	We agree. In the Context section we highlighted the poor physical and mental health profile of people with learning disabilities and briefly listed the likely reasons, such as under-diagnosis, mis-diagnosis, overshadowing, and failure to implement reasonable adjustment as you suggested. Untreated depression can be one of the many conditions that went undiagnosed and therefore untreated. The Committee made recommendations to address the shortcoming on overshadowing (1.3.4 and 1.7.3) .The Committee also recommended staff training to recognise and detect depression (1.5.6), and discussing with people with learning disabilities about changes in their conditions such as depression (1.5.14) Diana Kerr, University of Edinburgh: This reference relates specifically to pain relief needs of older people with learning disabilities and dementia. We did not explicitly address this in our guideline as the care and management of dementia in people with learning disabilities is not within our scope. However, we did make recommendations (1.6.7, 1.6.10, 1.6.11, 1.7.6) on pain management as part of care and management to support people with learning disabilities at their end of life.
The Downs Syndrome Association	Short	3	10	We would highlight that people with a learning disability are at a higher risk of experiencing inequalities in access to healthcare. This is true for both physical health and mental health (Emerson et al. 2011).	Thank you for your comment. We have added reference to the barriers that people with a learning disability face in accessing health care.
The Downs Syndrome Association	Short	3	16	Although prevalence of dementia is far higher in adults with Down's syndrome (55% of adults with Down's syndrome in their 50s have developed dementia) *Head E, Silverman W, Patterson D, Lott I (2012),* it is essential that relevant professionals undertake a differential diagnosis, to exclude other, treatable, conditions.	Thank you for your comment. The issue of diagnostic overshadowing is covered in recommendation 1.3.4.

				It is dangerous to make a presumptive diagnosis of dementia, especially in the absence of suitable training and use of appropriate assessment tools by a professional with a relevant qualification. We would cite the Dementia Action Alliance campaign around health inequalities and Seldom Heard Groups, which focuses on adults with a learning disability, see https://www.dementiaaction.org.uk	
The Downs Syndrome Association	Short	4	3	It should be remembered that many adults with Down's syndrome undertake an informal carer role for their parents and the nature of this mutually caring relationship is not always understood by services or adequately supported. Reference *Foundation for People with a Learning Disability Mutual Caring Project 2017.* There is often a lack of recognition of role that bereavement plays in the negative impact on the wellbeing of people with a learning disability. We are aware, through our Helpline services, of difficulties in referring people with a learning disability for counselling services.	Thank you for your comment. We have referred in the context section to the fact that older people with learning disabilities may also be carers for their parents, and this is also covered in recommendation 1.4.4.
The Downs Syndrome Association	Short	4	5	We would add that adults with a learning disability are more likely to be single and so less likely to have the support of a partner, as they age.	Thank you for your comment. Recommendation 1.1.10 highlights that some people with a learning disability do not have close family members. For those who do not have close family members, friends or carers, the committee ensured that people with learning disabilities have access to advocacy services (1.1.5, 1.1.11, 1.2.5). Many of our recommendations included advocates as one of the key members of the person's support network in decision making, accessing services and care planning.
The Downs Syndrome Association	Short	6	20	We are pleased that it has been noted that people with a learning disability experience many barriers to accessing healthcare and this should not be seen simply as the need to produce accessible information. In many cases the barriers are more about communication skills (in health professionals in explaining procedures or carrying out effective consultations) and also language difficulties in the person with a learning disability, who may find it very difficult to explain about symptoms or issues relating to their health. Many consultations are time-pressured and thus do not allow adequate time to undertake meaningful consultations with someone who needs additional explanation or more time to process information.	Thank you for your comment, and for your support for the recommendation. The Committee recognised the time pressure health professionals faced in trying to achieve effective and meaningful consultation with people with learning disabilities. The barriers in communications on both sides are challenging. The committee recommends that health professionals should allow sufficient time in identifying health needs (1.5.3) and that consultation should involve a practitioner who has a good relationship with the person and communicates well with them. (1.4.6). Ongoing training of staff is also important to ensure they have the skills and expertise to provide good quality care, including expertise in communication methods (1.7.6, 1.7.7) We anticipate that these recommendations will lead to a positive change in practice.
The Downs Syndrome Association	Short	7	26	Throughout the document mention is made of Mental Capacity. It is important to note that there is a low level of understanding of this amongst the general public and amongst certain groups of professionals. Decisions about capacity should be made on a decision by decision basis and support given to families to understand how to navigate this legislation.	Thank you for your comment. The committee agrees that mental capacity is particularly pertinent to this guideline population and they have made several references to important principles throughout the guideline (for example, in 1.1.8, and the new 1.1.11). However they are also mindful of the fact that NICE will shortly publish a guideline entirely focussed on 'Decision Making and Mental Capacity' so to avoid duplication, people are encouraged to refer to that guideline. In addition, the context section has been amended to specify legislation which is relevant to this guideline and that includes the Mental Capacity Act 2005.
The Downs Syndrome Association	Short	8	4	We are concerned that there is a huge local variance in the provision of advocacy services. Sometimes family members have difficulty in being recognised as an advocate for their relative and in some	Thank you for your comment. The committee discussed these issues at length during the development of the guideline. In 1.1.12 they emphasised the importance of prioritising the needs of the person,

				cases, a family member acting as an advocate might be inappropriate, as there could be a possible conflict of interest or competing needs between that of the individual and that of a carer (who's needs should also be recognised and met).	ensuring they are not overshadowed by the preferences of others, which is something the committee agreed was incredibly important. However in finalising the guideline they have also strengthened the emphasis on the important role played by advocacy, For example, they adopted and adapted a recommendation from another NICE guideline about offering advocacy wherever it is wanted or needed. We hope that this addresses your concerns.
The Downs Syndrome Association	Short	8	7	We are concerned that, too often, there is an assumption that families will continue to undertake a caring role, even when family-carers' health may have deteriorated and their capacity to cope is diminished.	Thank you for your comment. Please be assured that the committee were mindful of this potential difficulty and 1.1.9 was developed to try and change practice in this area by saying 'Regularly check people's willingness and ability to be involved in this way'.
The Downs Syndrome Association	Short	8	25 onwards	We have concerns in relation to funding – many services have cut-back provision, limiting access to only those with substantial or critical needs. This means that many individuals, who have a legitimate need for support are left unable to access support or professionals feel unable to put support in place until a lower-level need has escalated and the quality of life of the individual has deteriorated accordingly. Direct Payments – very variable uptake. Relies often on social services to inform a family of their entitlement to a direct payment in lieu of a service and many don't do this. Our Helpline received 47 calls in last year about poor understanding, problems with invoices, lack of offer, reduced payments. Coordination of support via a key working model would be welcome. This rarely happens. Various pilot projects have been run, but not replicated on a national basis. Access to short-break care has been cut in many areas. The value of this provision is important to both the individual with a learning disability and their family carers and often improves quality of life for each and means family-carers can continue providing support. Some anonymized quotes from family-carers who contacted our Helpline in recent months: "*They can no longer fund her support that was previously provided to meet social needs"* *"We will be meeting the head of the housing association soon to discuss this proposed change, and he is citing financial cuts as the reason for the changes."* *"They're cutting his budget 'because it's a new system'*	Thank you for your comment and for the information you have provided. Committee members are acutely aware of the resource pressures affecting the commissioning and provision of care and support. They thought at length about the resource implications of all the recommendations they made and on balance, felt the recommendations were achievable and indeed in some cases are already being rolled out. The committee did not review any evidence specific to the key worker model although they did review evidence about the importance of having a single learning disabilities expert or champion within health teams and to whom people and their families could refer for questions and clarification. This is captured in recommendations such as 1.5.9.
The Downs Syndrome Association	Short	9	9	We have concerns in relation to local services – there is a particular challenge of rural areas of UK, where choice may be severely limited or the need to travel to access support and services means they are inaccessible.	Thank you for your comment. The committee recognises these difficulties but aims to improve practice in this area through this recommendation, In addition, improved transport is also mentioned in recommendations 1.2.4 and 1.4.2.
The Downs Syndrome Association	Short	10	12	Whilst the benefits of telecare can be considerable, we have concerns that, in some instances, telecare can be seen as a cheaper alternative to face-to-face support and risk leaving individuals feeling isolated and lacking human contact. Telecare should always be seen as additional to, not replacing human-based contact.	Thank you for your comment. The committee agrees with the point you make and in response have edited recommendation 1.2.6 so that the second sentence reads, ' Use these technologies to complement but not to replace the support provided by people face to face.'
The Downs Syndrome Association	Short	11	4	We would wish to highlight The Down's Syndrome Association's project which promotes physical activity for people with Down's syndrome DSActive https://www.dsactive.org.uk/	Thank you for this information, which we will pass this on to endorsement team.

The Downs Syndrome Association	Short	11	12	It is our experience that many community transport services have been reduced in recent years and the funding of travel training for young adults with a learning disability has been cut, reducing the probability of adults with a learning being independent in their ability to travel and use public transport. – importance of travel training for adults at transition stage – this seems to have been cut. Dept. of Transport 2011 *Good Travel Training Guide* outlines good practice.	Thank you for highlighting this. The committee are aware of the issues you raise and this is reflected in 1.2.14 being a weak, 'consider' recommendation due to the lower threshold of evidence and concerns about resourcing. However, the committee did point out that lower cost, affordable solutions to providing transport should be considered and in fact already are being rolled out in some areas. For this reason the committee do feel that the recommendation is achievable.
The Downs Syndrome Association	Short	12	3	We fear that, due to high levels of staff turn-over, many professionals lack the longer-term involvement in the lives of the individuals with a learning disability they support. This seems to be particularly the case within social services social worker roles (who are often a key professional in assessing the needs of the individual). This lack of in-depth knowledge of the individual makes assessing needs more problematic, particularly when there is a need to be alert to changes in an individuals' usual pattern of behavior.	Thank you for your comment. We are aware that continuity of staff is hard to implement but anticipate the recommendation will initiate changes in this respect
The Downs Syndrome Association	Short	12	9	We would stress the importance of conducting baseline assessments of the cognitive ability and life skills of individuals with Down's syndrome and repeating this at intervals from age 30 onwards. We would cite the work of Karen Dodd (Surrey and Borders NHS Partnership Foundation Trust).	Thank you for your comment. The committee did not make recommendations about this because no relevant evidence was located through the systematic review, which would provide a basis for when or how often these assessments should be made. Repeated assessments would have resource implications and without the supporting evidence they could not be recommended. However, please note that recommendation 1.3.1 states that assessments be conducted as early as possible.
The Downs Syndrome Association	Short	13	3	It is our experience amongst family-carers who use our services that there is a low-level of awareness of the right to have a Carers' Assessment and thus uptake is very low.	Thank you for your comment. We have highlighted these issues in recommendations 1.3.7 and 1.3.9. We anticipate that the recommendations will lead to positive changes in practice.
The Downs Syndrome Association	Short	15	11	Whilst we agree that supporting an individual to remain living at home is preferable (and outcomes more favourable for individuals by keeping them in a familiar environment in early-stage dementia), we fear that over- reliance on adaptations and telehealth solutions could leave individuals very vulnerable. We are aware of excellent research on the impact that the physical environment has on the progression of dementia on people with a learning disability, which has been undertaken by Diana Kerr (University of Edinburgh).	Thank you for your comment. The Guideline Committee agreed that technology, telecare and telehealth must not replace human contact and care. We've amended recommendation 1.2.6 to highlight this point. Recommendation 1.4.10 states that technology and telehealth monitoring can be considered as additional support to enable older people with learning disabilities to stay living in their own home.
The Downs Syndrome Association	Short	16	13	We feel this statement needs strengthening and that medical examinations should occur in a familiar place wherever possible, rather than this simply being an "aim". GP home visits less likely now than ever. Amalgamation of GP practices or Walk-In Centres in some locations means the relationship between an individual and their GP is less likely to be personal, a GP may not even know the person who consults them.	Thank you for your comment. Recommendation 1.5.4 states that the person has a choice as to where a medical exam takes place, also the place be familiar to them, welcoming and appropriate to their needs. The committee did not agree any further changes in light of your comment.
The Downs Syndrome Association	Short	16	18	We very much welcome the "differential diagnosis" approach to supporting people with a learning disability as they age and stress the importance of investigating treatable conditions listed. Too often, decline in older age is attributed to the inevitable consequences of dementia or is a result of diagnostic overshadowing and seeing symptoms of decline as being associated with the underlying learning disability.	Thank you for your comment. We agree and have revised the recommendations 1.7.1 to 1.7.5. to address these issues. We have also specifically cited 'diagnostic overshadowing' in recommendation 1.3.4 and defined the concept in 'terms used' to which there is a direct hyperlink from the recommendation.
The Downs Syndrome Association	Short	17	7	We would cite the useful added value that a Circles of Support model can bring to working with an individual http://www.circlesnetwork.org.uk	Thank you for your comment. The committee were aware of the circles of support model which used a more generic concept of 'support network' to reflect the range of people that the older person with a learning disability may wish to have involved in their lives. However, the systematic review did not locate any evidence from empirical studies relating to this model and without such supporting evidence the committee was unable to make a specific recommendation about this approach.

The Downs Syndrome Association	Short	17	23	Although adults with a learning disability have an entitlement to an Annual Health Check, we know that update is low and varies significantly across the UK. We would suggest that Annual Health Checks be provided as a direct offer (like Public Health England Screening service), with an opt-out, rather than individuals having a 'right to request' an Annual Health Check, as many are unaware.	Thank you for your comment. We have revised the recommendation (1.5.12) making specific reference to offering an annual health check to older people with learning disabilities, who now do not have to make a request to have one
The Downs Syndrome Association	Short	18	11 through 20	This assumes that people will access an Annual Health Check and as previously stated, many don't.	Thank you for highlighting this. The committee have reviewed the recommendations and now place a greater emphasis on recommending that annual health checks are made available and to be offered to all older people with learning disabilities, who now do not have to request to have one. We anticipate that this and the other recommendations about screening and checks will help improve practice in this area.
The Downs Syndrome Association	Short	19	5	We would cite the Down's Syndrome Association's Accessible Health Booklet as an example of good practice, which can support the work of GPs. https://www.downs-syndrome.org.uk/download-package/health-book/	Thank you for your suggestion. We are unable to recommend specific tools or approaches without supporting evidence of effectiveness – which was now found for this. However we will pass this information to the endorsement team.
The Downs Syndrome Association	Short	20	28	We feel that the work of Learning Disability Champions, working within hospital settings needs extending. Provision is patchy and the workload of many who hold these posts hinders meaningful engagement. Awareness and adherence to hospital passports is also piecemeal. Family carers often feel that they HAVE to stay for the duration of their loved-one's in-patient stay. This is unacceptable and impractical.	Thank you for your comment. The committee recognise the problems you highlighted. The recommendations (1.5.28, 1.5.29) state that hospitals should make it easier for family carers to stay (if they so choose to) with the person in hospital, taking into consideration of their willingness and ability to provide support, and their relationship with the person (as in 1.5.32). The recommendations did not intend to imply that family carers must stay and provide care to the person when they are in hospital. The committee felt that the recommendations about the learning disability champion as well as those about staff continuing to offer health and personal care despite the presence of family carers will lead to positive changes in practice.
The Downs Syndrome Association	Short	22	1	Due to scarcity of spaces in specialist learning disability residential care services, it is often our experience that adults with Down's syndrome are more likely to experience a delay in their discharge from hospital, especially where a dementia placement is required. Specialist learning disability / dementia dual registered provision are rare, as those settings which specifically accommodate adults with early onset dementia (age of onset of dementia in adults with Down's syndrome is typically mid 50s). If individuals with Down's syndrome, who develop dementia, are moved into dementia units, they are likely to be 30 or 40 years younger than many other residents, making this provision inappropriate.	Thank you for your comment. The committee is well aware of the problems you highlight and they feel they are already covered in the guideline, for example in recommendations 1.5.32 to 1.5.36 about transfer of care from hospital as well as the recommendations about ensuring people can continue to live in their current accommodation, if this is their wish.
The Downs Syndrome Association	Short	23	9	We feel that much needs to be learnt about End of Life Care for adults with a learning disability. We would reference Todd et all, University of South Wales study (2017), which showed that even though majority of professionals involved in the care of an older person with a learning disability had expected their death, an End of Life plan was rarely in place. Their study also showed that of the individuals who died during the course of their study 70% were adults with Down's syndrome, who had developed dementia. Support should be provided to enable an individual to remain at home for as long as possible or to die at home, if that is their wish. However, far too frequently, individuals (especially those with dementia) are moved to nursing care provision, because this is seen as cheaper alternative.	Thank you for your comment. We do anticipate the recommendations will lead to positive changes in this respect. Please also be aware of a NICE guideline on care of dying adults in the last days of life in recommendation 1.6.13, which is highlighted in 1.6.13 of this guideline.
The Downs Syndrome Association	Short	25	5	We would strongly advocate for improved access to specialist training on supporting adults with Down's syndrome for health and social care staff working in the field. The Down's Syndrome Association facilitate a range of training opportunities relevant to this	Thank you for your comment. The committee agrees with this important point and believe that it is covered by the detailed recommendations.

				area, particularly focusing on ageing and dementia www.downs-syndrome.org.uk/about/training/ageing-and-dementia	
The Society and College of Radiographers	Short	17	18	In addition to health records (staff in imaging and radiotherapy departments do not always have access to health records); other methods of communicating information must be included. For example, patients referred for diagnostic tests and treatments – pass information on about patient needs prior to attendance. This should be done at the time of referral for example via electronic requesting systems or paper based requests for appointments. Staff must ensure that older people with learning disabilities, when being treated as In-patients and transferring between departments, have a hospital passport available. The key principle is to keep all staff involved in the care of the patient informed about their needs.	Thank you for your comment. Having discussed your point as well as those raised by other stakeholders, the committee agreed some changes including that a person's learning disability and any reasonable adjustments should be recorded in their health records and that this information should be shared 'when making referrals'.
The Society and College of Radiographers	short	18	19	Please note that breast screening is not a preventative service; it involves the use of a small amount of ionising radiation to diagnose abnormalities and cannot prevent disease. Indeed, a small risk of inducing disease is associated with the use of ionising radiation (X-ray).	Thank you for highlighting this. We have revised the recommendation to clarify this point.
The Society and College of Radiographers	short	20	18	Imaging and radiotherapy departments may not be able to comply with this standard due to the nature of staff shift and on-call working patterns. Alternatively a liaison radiographer could be appointed for older people with learning disabilities in imaging and radiotherapy departments; in order to assist with coordination of care and pre-visits.	Thank you for your comment. The committee acknowledges your point but felt that adding 'where possible' to the recommendation could imply that it does not need to be implemented. In practice, they feel that even if it is difficult to achieve from an organisational point of view then practitioners will seek alternative arrangements to attempt to meet the standard – much in the same way as you have suggested.
Thera Trust	Full	General		Overall the document sets a good standard and highlights areas we are generally all concerned with and is very comprehensive.	Thank you for your comment, and for your support for the guideline.
Thera Trust	Full	General		There is a need for training for staff working with people who have Dementia, is this covered fully enough?	Thank you for your comment. Training to be able to provide care and support for adults with learning disabilities as they grow older and their needs change are covered in some detail in section 1.7, especially 1.7.3.
Thera Trust	Full	General		Concerns about hospital staff knowledge of learning disabilities and how this can be addressed	Thank you for your comment. We have considered this, and think it is covered in section 1.7, which applies to the workforce in health and social care. There is also a specific section (1.5) about providing support to older people with learning disabilities in health settings, including hospital.
Thera Trust	Full	General		Concerns about how the guidance can be implemented with the very limited resources available in hospitals and social care.	Thank you for your comment. The Guideline Committee acknowledged the challenge that limited resources will have on implementing the recommendations. The recommendations are considered to be aspirational but achievable. In the case of a limited budget, using existing resources differently may have to be considered.
Thera Trust	Full	15-17		Planning and reviewing care and support section is clear and concise.	Thank you for your comment.
Thera Trust	Full	20-21		Primary care section needs some reference to the availability of home visits from medical professionals	Thank you for your comment. The issue of increasing 'home visits' was not identified in the evidence reviews although the guideline is clear about the need for health checks and appointments to take place in a familiar environment and – as far as possible – in a location chosen by the person.
Thera Trust	Full	22	588	Experiences are that this rarely happens and it is often providers staff who deliver personal care in hospital.	Thank you for your comment. We hope that this recommendation will lead to improvements in this area.
Thera Trust	Full	27		Training should include the MCA- consent and advance decisions	Thank you for your comment. This recommendation has been amended to include reference to the Mental Capacity Act 2005.
Think Local Act Personal	Short	General	General	Broadly we are supportive of the content and message of the guideline.	Thank you for your comment, and for your support for the guideline.

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Think Local Act Personal	Short	General	General	The guideline could go further to describe the landscape of the system needing to support older people with a learning disability in the context of the Care Act, with a focus on wellbeing, with an associated shift to a focus on solutions rather than services. This could easily be achieved by adjusting the language used. The style of writing is clear	Thank you for your comment. The recommendations aimed to support current thinking in relation to meeting people's needs, rather than providing services. In response to your feedback, we have reviewed the language in the guideline and ensured that this is reflected throughout, for example changing using words such as 'offer' instead of 'give'.
Think Local Act Personal	Short	General	General	The guideline could be perceived as unrealistic in the current and enduring challenging economic climate as there is little acceptance in it that resources are shrinking and some of the 'service landscape' described is being reduced to minimal levels. E.G. Transport is being challenged more and more. The guideline might set unrealistic and unachievable expectations for people.	Thank you for your comment. The Guideline Committee considered carefully the resource impact of the recommendations. The recommendations are judged to be aspirational but achievable. Particularly in the case of the provision of transport, although this might involve some additional upfront investment (depending on existing provision) the GC were content that spending in this area would improve outcomes for individuals (maintaining connections, attending appointments) and avoid higher costs being incurred later, for instance through crisis care and unplanned admissions.
Think Local Act Personal	Short	General	General	The guideline sets out a context where 'many older people with learning disabilities……are not known to public services' The guidance does not address the best way/present evidence for commissioners to address this issue. This will be key to understanding whether the guideline is realistic and deliverable financially.	Thank you for your comment. You make an important point although no evidence was located that would provide the basis for a specific recommendation to address this issue. However, Committee members were clearly aware of the dilemma and did develop recommendation 1.2.1 and 1.2.2 to ensure that health and social care commissioners understand the needs of their population. It is recommended that this is in part achieved by identifying the number of older people with learning disabilities and ensuring age appropriate services and resources are available in the community.
Think Local Act Personal	Short	General	General	The guideline is not clear about the tension that practitioners need to manage between hearing the views of older people with a learning disability and hearing families views. The Easy Read version clearly states this well	Thank you for highlighting this. The committee considered your point but feel that they the balance between the needs of families and the needs of individuals is addressed. However they did agree to add a new recommendation (1.1.11), adapted from another NICE guideline about the importance of referrals to advocacy services, regardless of whether people have family and friends available to help with the planning and provision of support.
Think Local Act Personal	Short	General	General	Given the importance of 'advocacy' for this group of people, consider adding this in within 'overarching principles', it seems to be added a bit piecemeal within/across the document	Thank you for your suggestion. The Committee members agreed that the role of advocacy could have been acknowledged and promoted more in the guideline – especially where people may not have family and friends to help with the planning and provision of support. The Committee therefore agreed to strengthen the focus on advocacy in the overarching principles section, not least by adapting a recommendation from another NICE guideline, which states that independent advocacy should be offered wherever it is wanted or needed, in line with the Care Act 2014, the Mental Capacity Act 2005 and the Mental Health Act 2007 (see 1.1.11).
Think Local Act Personal	Short	3 and 4	30 and 1	This paragraph seems to be about sensory impairments, dental checks seem misplaced in this context, should the point be more about broader health checks and their importance	Thank you for your comment. Reference to dental checks has been moved as you suggest.
Think Local Act Personal	Short	4	33	Is 'end of life care' a specific service? Suggest removing end of life care and add 'be supported to die with dignity' at the end of line 25. (Health may see this as a specific 'service' in terms of expressing many aspects of its provision as pathways)	Thank you for your comment. Although the GC were content that end of life care is an accepted and well understood term for services provided support at the end of life, we amended the sentence in the 'purpose of this guideline' to read '……..and supporting access to services including health, social care, housing and care at **the** end of life.**'** We believe that this clarifies that we're referring to a range of different support and care provided to people at the end of their lives.
Think Local Act Personal	Short	6	6	Replace 'Give' with 'Provide' – give reinforces the notion of professional 'gifting' of support expressed as services rather than a citizenship view of living a good life with support in a community	Thank you for your comment. The recommendations have all been reviewed to ensure the language is empowering and not benevolent. For this recommendation, 'give' has now been completely removed

					and replaced with 'Ensure older people with learning disabilities have the same access…' We hope this addressed your concern.
Think Local Act Personal	Short	6	9	Consider removing commissioners. Commissioners wouldn't normally make reasonable adjustments, they would do this through requiring their contracted provider to do it, either through recommissioning/re-contracting, or contract management. A point could be added to highlight the importance of the commissioning role in ensuring this happens.	Thank you for your comment, which was supported by another stakeholder. To address the issue the recommendation has been edited to reflect that providers have a statutory responsibility to meet the Accessible Information Standard but that practitioners have a key role in implementing the standard.
Think Local Act Personal	Short	8	22	Suggest replacing the wort 'services' with 'care and support'	Thank you for your comment. This amendment has been made in the final version of the guideline.
Think Local Act Personal	Short	9	12	Are day opportunities relevant services for family members, carers and advocates themselves?	Thank you for your comment. The committee aimed to encourage commissioners and providers to think in the broadest possible terms about the care and support that would benefit families and carers and agreed not to limit it by removing any items from this list.
Think Local Act Personal	Short	10	6	Respite care whilst looking like a service to the person is about the Carer having a break. Older People with a learning disability don't need respite care, Carers do, it's replacement care to enable the Carer to have a break	Thank you for your comment. Recommendation 1.2.6 in the draft guideline applies to services for older people with learning disabilities *and* their family members and carers.
Think Local Act Personal	Short	10	5-10	This list represents the staid, traditional list of services that have developed, other things could be listed to underline and encourage a shift away from this list towards enabling people to have a good life in old age	Thank you for your comment. The recommendations generally do emphasise the importance of promoting independence and enabling people to live how they wish. However recommendation 1.2.5 is specifically about housing options, and is based on the evidence reviewed.
Think Local Act Personal	Short	10	22-25	With reference to comment above, this is an excellent way of describing this landscape, older people with learning disabilities may need support to have this access	Thank you for your comment and your support for this recommendation.
Think Local Act Personal	Short	13	11-12	Consider adding something about providers, they will have key information and intelligence to offer	Thank you for your comment. The committee acknowledges the important contribution that providers make but this recommendation is specifically based on evidence about the importance of involving families or advocates in person centred planning, which of course will be conducted by and alongside providers.
Think Local Act Personal	Short	13	13-14	I think this needs to be clearer. This may disengage many local authority leaders as 'transport' is commonly off the unwritten list of things LA resources can provide. It may be better to write something about getting about in the community being a critical factor to achieving and maintaining independence, and consideration needs to be taken of enabling the person to get about to do the things that are important to them	Thank you for your comment. Recommendation 1.4.1 already makes reference to including people's transport needs in addressing their care and support needs – in order to meet a broad range of needs. In earlier recommendations, commissioners and providers are also urged to provide 'accessible opportunities' to engage in education, working and volunteering and a specific recommendation describes a range of options for local authorities to provide schemes to make transport easier for people. On balance, the committee feels your point has been addressed. Recommendation 1.214 is not intended to imply that local authorities fund all those suggested transport services, just that consideration should be given about meeting people's transport needs with the examples listed being a range of options derived from the evidence and from the committee's expertise and experience about existing schemes. The committee felt that local authorities should be encouraged to take a creative approach to transport solutions, building on existing schemes and/ or working with voluntary providers.
Think Local Act Personal	Short	14	6-8	This could be read as involving more than one practitioner – this is unrealistic and is likely to disengage LA leaders and commissioners	Thank you for your comment. The bullet point is not intended to suggest that multiple practitioners should be involved – simply to say that whoever the practitioner is (and it could be any one of a number of practitioners) should have a good knowledge of local services.

Think Local Act Personal	Short	15	18-20	Does this need 'to ensure the persons views are effectively heard' adding	Thank you for your comment. We have amended recommendation 1.4.12 to clarify this point.
Think Local Act Personal	Short	22	21-24	Does something need adding about making sure this information is accessible-a reminder, don't just use standard information about dementia	Thank you for your comment. The committee believe this is already very well covered in the guideline, for example in recommendations 1.1.5 and 1.5.37.
Think Local Act Personal	Short	27	14-16	I think you are conflating two types of social care worker here. Where you refer to practitioner, you are largely talking about social care assessment staff with in Local Authorities. These workers do not provide care and support You also refer to social care staff, or older peoples services workers. I think you could helpfully add another category which might be care workers, or staff providing care and support.	Thank you for highlighting this. The committee are using practitioner in the broadest sense of the word to refer to anyone providing care and support (including assessment).
Vision UK	Full	General	general	As an addendum, we are surprised that there was very little in the supporting evidence section on research around access and facilitation to optometric checks amongst older adults with learning disabilities. There has been a number of studies including a longitudinal study of adults aged over 50 years of age in the Netherlands (see *Van Isterdael, 6220 institutionalised people with intellectual disability referred for visual assessment between 1993 and 2003: overview and trends, and Van Splunder et al. Prevalence of visual impairment in adults with intellectual disabilities in the Netherlands: cross sectional study, Li (2015) The challenges of providing eye care for adults with intellectual disabilities*). The latter in particular notes how improvements to deinstitutionalise people with learning disabilities have not been accompanied by improvements in primary eye care. As well as these international studies, a number of studies in the UK that have recommended targeted optometric examination of people with learning disabilities (eg. *Woodhouse et al, A. (2000), The prevalence of ocular defects and the provision of eye care in adults with learning disabilities living in the community; Starling, S et al (2006), 'Right to sight' Accessing eye care for adults who are learning disabled; Stanford and Shepherd (2001). A vicious circle: visual impairment in people with learning disabilities)*	Thank you for this information. These studies were identified by our systematic search but did not meet our criteria. Li (2015) – Excluded as age of population not specified. Excluded – a review to discuss prevalence, age of population not specified. Starling et al. (2006), Excluded – as this is a prevalence study (not one of our included study types), also population involved people with disabilities of all ages Van Splunder (1993, 2003); Woodhouse et al (2000); Stanford and Shepherd (2001) - These 4 studies were published pre-2005, outside our 10-year search dates.
Vision UK	Short	General	general	In October 2017 VISION 2020 UK became Vision UK. We are the independent partnership organisation which will work with other organisations in the eye health and sight loss sector for the benefit of blind and partially sighted people, their communities and the general population including those at risk of sight loss. The Learning Disability Committee focuses on the specific needs of children and adults who have a learning disability and provide a unified approach to issues relating to vision and learning disability across the UK. The Committee involves representatives from our members which include SeeAbility, The Optical bodies and LOCSU, The Royal College of Ophthalmologists, The College of Optometrists, RNIB, RNIB Scotland, ABDO and The GOC.	Thank you for your comment. We have amended recommendation 1.5.16 to make reference to informing people about, and helping them to access, sight tests. Recommendation 1.3.4 also makes reference to diagnostic overshadowing, with examples provided in the 'terms used' section.

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				This response also supports the response you will have received from SeeAbility Adults with learning disabilities are 10 times more likely to have serious sight problems than the general population (see research commissioned by RNIB and SeeAbility from Improving Health and Lives https://www.seeability.org/Handlers/Download.ashx?IDMF=511dbb2c-08fb-40e8-b568-a2ed38a4ea13). This report shows that as sight problems increase with age, as people with learning disabilities get older the prevalence of visual impairment or significant refractive error grows (an estimated 14% of people with learning disabilities over 50 are sight impaired or severely sight impaired, and over 56% have refractive error), as will the risk of age related macular degeneration, cataracts and other eye health conditions. People with learning disabilities may be at greater risk of accidents and falls, or need more costly packages of support from health and social care due to avoidable sight loss. VISION 2020 UK/Vision UK very much welcome the draft guideline for highlighting actions that can be taken to support older people with learning disabilities, and in particular for giving profile to the risk of sensory impairments in people with learning disabilities and actions that health professionals can take. In particular the focus on accessible information is helpful and we would be delighted if NICE, when publishing the guideline, could include signposted information to SeeAbility's easy read information, such as information on having a sight test, and eye conditions that are likely to present in people with learning disabilities, such as cataract. https://www.seeability.org/looking-after-your-eyes It is very important to note that someone with a learning disability may not be able to effectively communicate visual problems or symptoms or visual impairment can often be misattributed to someone having a learning disability, and overlooked. Therefore access to sight tests is extremely important in understanding if someone has a problem with their vision. We have supported people to access eye care: surgery for cataracts, and refractive error correction for age related presbyopia – in many cases the individuals were thought to have become 'withdrawn', or 'challenging' or were even having tests for early onset dementia, before their vision status had been established.	
Vision UK	Short		1.2.7	While we welcome the statement in 1.2.7 that commissioners should seek to identify where there are gaps in community optometry and dental services for older people with learning disabilities and seek to address those gaps, it is actually the responsibility of NHS England to provide the funding and framework for the operation of primary optometric care and not clinical commissioning groups as stated. Unfortunately the NHS England sight testing contract has overlooked the needs of those with learning disabilities, by providing no incentive to provide longer, reasonable adjusted appointments in practices or day centres. Any optometric appointment in these	Thank you for your comment and the information you provide, which the committee discussed. They agreed to remove the specific reference to 'clinical commissioning groups' and instead refer more generally to 'Commissioners' in the recommendation.

				circumstances pays £21.31, the same as any routine 'high street' sight test. In a few local areas, pathways have been developed for people with learning disabilities through commissioners prepared to pay to 'fill the gap' in the funding system, but this isn't a solution to getting national coverage of services for people with learning disabilities. NICE should either add into 1.2.7 "address those gaps *with NHS England*" rather than seek to encourage local commissioners to address a system they have no commissioning responsibility for, or more preferably explicitly state "*that NHS England should seek to address any gaps in community optometry services through its role as primary optometry commissioning body.'*.	
Vision UK	Short		1.5.6	We very much welcome the statement in paragraph 1.5.6 to consider training for people and their family members and carers in recognising and managing age- related conditions such as sight loss. However, we question who this statement is directed to – it seems to be healthcare practitioners – but it should be for commissioners to commission this training so healthcare practitioners can operationalise it.	Thank you for your comment. This recommendation has been amended so that it is addressed at both commissioners and providers.
Vision UK	Short		1.5.9	We also welcome the statement under 1.5.9 on identifying people with knowledge and skills within primary care teams, and this should include optometrists and dispensing opticians within primary eye care.	Thank you for your comment. The committee deliberately avoided making specific reference to the practitioner who could take on this role as it will vary in different teams. Therefore they decided not to make the change you suggested although please note that in other recommendations, specific reference to optometry services and sight loss have been made in response to your feedback.
Vision UK	Short	General	general	Under health checks and screening, NICE emphasises the importance of being registered with a dentist (paragraph 1.5.15 and advice for dentists 1.5.22). There is no mention about asking about recent sight tests as well as ensuring commissioners ensure that people with learning disabilities can make the best use of their vision. **We feel there is is a very strong argument for this section to include more on this subject.** **We suggest** ***"Given the high risks of sight problems in people with learning disabilities ensure the person is accessing regular sight tests with a community optometrist and that support staff are aware of the risks and the need to support the person to make the best use of their sight. This includes ensuring the person has access to and is supported to wear the right spectacles, as well as access to onward treatment and surgery, and maintenance of treatment in the community. This may also include the need for vision rehabilitation services to support independence".*** Our reasons and evidence are as follows: • Given the risks of serious sight problems is much higher in this group, any problem with vision is much more likely to	Thank you for your comment. We have amended recommendation 1.5.17 to make reference to informing people about, and helping them to access, sight tests. With regard to commissioning, recommendation 1.2.7 states that commissioners should identify gaps in community optometry services. In addition, 1.5.14 under 'health checks and screening' recommends that practitioners ask people about and monitor people for symptoms – with hearing loss and sight problems at the top of that list of examples, Finally, 1.5.6 recommends that training is commissioned for people and their families to help them recognise and manage age related conditions, again with hearing and sigh loss and the top of the list of examples, Hopefully this reassures you that the guideline does not assume that annual health checks are the only opportunity for identifying and managing sight loss problems. Thank you for highlighting these additional references. We referred back to our original search to understand why they had not been located. Specifically: Evenhuis (2009) was not located by the search because the term 'older people' did not appear in the title or abstract. Codling (2013) was not located by the search because the term 'older people' did not appear in the title or abstract. Carey et al (2017) was published after we conducted the searches. This could potentially be included in any future updates of the guideline.

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				impact on independent living than dental problems. This can be a gradually developing need for refractive error correction (age related presbyopia, manifest hyperopia) or development of cataract or open angle glaucoma, or more urgent conditions may develop such as corneal ulcers, retinal detachment or acute glaucoma which need prompt treatment. If there is poor access to eye care then, subsequent visual impairment may compound pre-existing disability in some people with learning disabilities. Evidence of compounding issues: Evenhuis H M, Does visual impairment lead to additional disability in adults with intellectual disabilities? Journal of Intellectual Disability Research vo 53 No. 1 pp 19-28, 2009. • Nor should NICE rely on annual health checks as a roundabout way of ensuring vision is checked. The problem with 'health checks' is if interpreted as the GP annual health check, is that GPs do not undertake sight tests nor comprehensive eye examinations, and there is evidence that people are not being told about sight tests during the annual health check. There is also evidence that people may misunderstand what types of checks they are having on their sight – for example people who go to diabetic eye screening may think they are having a full sight test. Evidence of poor reference to vision in GP health checks: Codling, M. (2013), 'Eye Know': translating needs from annual health checks for people with learning disabilities to demand. British Journal of Learning Disabilities, 41: 45–50; Carey et al (2017). An evaluation of the effectiveness of annual health checks and quality of health care for adults with intellectual disability: an observational study using a primary care database. Population Health Research Institute. Health Services and Delivery Research Volume 5, Issue 25, • There is published evidence that awareness of the eye care needs of people with learning disabilities amongst staff in residential and day care services can be low, perpetuating problems in identification and management of sight problems in these environments. And as reporting of sight problems is often symptom led this puts people with communication difficulties at major risk of not getting the eye care they need. This includes support to continue wearing of their glasses. Evidence of low awareness: Newsam, H., Walley, R. M. and McKie, K. (2010), Sensory Impairment in Adults With Intellectual Disabilities—An Exploration of the Awareness and Practices of Social Care Providers. Journal of Policy and Practice in Intellectual Disabilities, 7: 211–220;	Newsham et al (2010) was not located by the search because the term 'older people' did not appear in the title or abstract. Leamon et al (2014) was not located by the search because the term 'older people' did not appear in the title or abstract.

				Leamon, S. et al (2014). Improving access to optometry services for people at risk of preventable sight loss: a qualitative study in five UK locations. J. Public Health (Oxf). 1–7. There is also a general lack of awareness by those brokering or commissioning services for older people with learning disabilities in respect of rehabilitation services for those with visual impairment, and the benefits these services provide in maintaining independence and daily living skills.	

Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees