# Care and support of older people with learning disabilities

## Consultation on draft scope
## Stakeholder comments table

**11/08/15 – 08/09/15**

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| 1.01 | SH | Bedfordshire and Luton Fair Play | General | General | The revised draft looks very sensible, having picked up most of the points made during the scoping workshop. I think this should set an effective template for the future guidance. | Thank you for your support. |
| 11.01 | SH | British Institute of Learning Disabilities | General | General | BILD warmly welcomes the development of this guideline by NICE | Thank you for your support. |
| 11.02 | SH | British Institute of Learning Disabilities | General | General | The language used is too ambiguous for example the terms "carer" "care worker" "care and support practitioners" seem to be used interchangeably without a clear definition of the roles covered by each term. | Thank you for your comment. We agree that it is potentially confusing to use both 'care worker' and 'care and support practitioner' in the scope and have therefore changed 'care worker' in the outcomes section to read 'practitioner'. The term 'carer' is always used to refer to someone who helps another person (usually a relative or friend) in their day-to-day life. This is not the same as someone (for example a practitioner) who provides care professionally or through a voluntary organisation. Where the term 'carer' is used in the final guideline, a glossary definition will be provided. |
| 11.03 | SH | British Institute of Learning Disabilities | General | General | There is still very little recognition of the mutual caring that happens when older people with a learning disability live with frail older parents and the balance of care changes between them. | Thank you for highlighting this. We agree that mutual caring is an important issue in the context of this topic, which is why it is cited in section 3.1 of the scope (key facts and figures). However, given its importance, the Scoping Group agreed to give it further emphasis, changing the wording of section 1.3 (key areas that will be covered) to read "**Identification, assessment and regular review of health and social care needs in older people with learning disabilities and** |

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| | | | | | | **assessment of their carers' needs and their own needs as carers"** |
| 11.04 | SH | British Institute of Learning Disabilities | General | General | There is little recognition of the different experiences and expectations of older people and their families from different age cohorts e.g. those of older people with a learning disability aged 50 and aged 80, and those of older family carers in their 60s and 90s. | Thank you for your comment. We recognise that 'older people with learning disabilities' are a heterogeneous population with different experiences, needs and expectations. This is partly why we have avoided introducing an age cut off for describing 'older people'. It is possible that very specific issues relating to the cohorts you describe will be identified in the review of evidence and therefore may feature in the final guideline. However, no changes to the scope have been made in light of your comment. |
| 11.05 | SH | British Institute of Learning Disabilities | General | General | There is little or no explicit reference to the different, but potentially complimentary roles of specialist learning disability and specialist older peoples' services. | Thank you for your comment. The context section of the scope states that the guideline will cover the contribution made by social care, health and housing services to the wellbeing of older people. This includes both specialist learning disability and specialist older peoples' services and the guideline will also focus on improving the way that all those services work together to improve person centred outcomes for older people with learning disabilities. |
| 11.06 | SH | British Institute of Learning Disabilities | General | General | There may be a need to explicitly focus on the reasonable adjustments that specialist health and social care services often accessed by older people need to make in order to make their services inclusive for older people with a learning disability e.g. dementia and diabetes services, Parkinson support, palliative care services. | Thank you for your suggestion. We agree about the importance of making reasonable adjustments to ensure health and social care services are full accessible. However, this is likely to be an issue that will be identified in the review of evidence underpinning the guideline rather than something that needs to be added to the scope. We have therefore made no changes to the final scope in light of your comment. |
| 11.07 | SH | British Institute of Learning | General | General | It would be good to recognise the need for people with a learning disability to have more information and support to understand the ageing process and about active ageing, also about issues often | Thank you for your comment. We agree about with your point, which is why one of the key areas that will be covered (section 1.3 of the scope), is |

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| | | Disabilities | | | experienced by older people e.g. thinking about retirement, different housing options, staying health, planning for the future including end of life care, writing a will, etc. | 'interventions and elements of care and support for older people with learning disabilities, including the provision of practical and emotional support (for example, relating to finances, retirement, bereavement and life changes)'. |
| 11.08 | SH | British Institute of Learning Disabilities | General | General | The guideline rightly focused on the care and support of older people with a learning disability but has currently has little or no reference to the need for person centred approaches, personalised support. | Thank you for your comment. The importance of personalised care and support is central to this scope and we have tried to reflect this in the content and use of language throughout. The focus of the guideline is described in section 3 as being on "**improving the way that care and support practitioners work…to maximise person-centred outcomes for older people with learning disabilities."** In addition, one of the two categories of outcomes of interest to the review of evidence underpinning the guideline is 'person-focused outcomes', which includes independence, choice and control over daily life, capability to achieve desired person centred outcomes and social care related quality of life'. The final guideline will include recommendations about delivery care and support to older people with learning disabilities based on the principles of person centred care. |
| 6.01 | SH | Care and Repair England | General | General | The Care Act 2014 defines well-being to include the suitability of living accommodation.<br><br>It expects local councils to ensure the integration of care and support includes housing. There is recognition that the suitability of living accommodation is a core component to enable people to live independently.<br><br>As a result we ask that the guideline includes housing as an important consideration in the provision of care and support for | Thank you for your comment. We agree about the importance of appropriate housing and of planning for the future housing needs for this population. As for your specific suggestions in relation to housing and the scope, we have dealt with these in the remainder of the table. |

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| | | | | | older people with learning disabilities and their carers.<br><br>We make the following general points on the importance of considering housing alongside care and support<br><br>•Many of the health conditions people face are exacerbated by poor and inappropriate housing and can be alleviated by improving and adapting people's homes. This factor should be considered in the provision of health and social care interventions to support wellbeing<br>•Whilst we would not expect social care and health practitioners to deal with housing issues, per se, we would argue that housing needs to be considered in any social care assessment and that staff need to know about the common housing issues and who to contact locally to ensure that people's housing circumstances are addressed in so far as they impact on a persons' wellbeing.<br>•There is an expectation in the Care Act that housing factors are a part of an integrated assessment.<br><br>Whilst the Context for the Scope identifies the importance of the contribution of housing as well as health and social care to people's wellbeing we believe references to – and consideration of – housing factors need to be more prominent throughout the Scope. | |
| 6.02 | SH | Care and Repair England | General | General | We would like the Context for the work to be broadened to consider the issues for older people living in, and wanting to remain, in mainstream housing. Work we undertook in 2008 looked specifically at the needs of older people with learning disabilities living in owner occupied homes. We identified that support in undertaking both repairs and adaptations and advice and information can be significant in supporting people to live well at home. In our work we identified that people were not getting the practical and financial support that they needed and we set out an agenda to address the issues. This included crisis support as well | Thank you for your comment. We agree about the importance of supporting people to remain in mainstream housing, where it is their wish to do so. This is reflected in the context of the scope which describes how, when their parents die, the older person with learning disabilities may remain in the family home or, due to inadequate support, have little choice but to move to a care home, which in itself may be inappropriate and at odds with the person's wishes. |

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| | | | | | as preventative services recognising this this group in local care, health, housing and wellbeing strategies.<br><br>The report can be found at http://careandrepair-england.org.uk/wp-content/uploads/2015/01/Living-on-the-Edge-final.pdf<br><br>We appreciate that the section on the Context for the guideline (Chapter 3) recognises the number of older people living with learning disabilities who remain in a family home when parents have died. We would, however, like to see more consideration of the impact of people's housing circumstances and ways to provide practical help and support for older people with learning disabilities to repair, adapt and manage their homes.<br><br>In meeting care and support needs we would want the quality and suitability of the home to be an important factor in delivering support for wellbeing. We have picked this up in specific comments on page 12. | In these and other circumstances support with repairs and adaptations is clearly crucial and to ensure this is sufficiently well reflected in the final scope, we have amended the wording in the 'areas that will be covered' (section 1.3). Area 5 now refers to **'interventions and elements of care and support for older people with learning disabilities, including the provision of housing related support, including equipment, adaptations and assistive technology'.** |
| 7.01 | SH | Department of Health | General | General | I wish to confirm that the Department of Health has no substantive comments to make, regarding this consultation. | Thank you, this is noted. |
| 2.06 | SH | Lancashire Care NHS Foundation Trust | General | General | Reference to high risk of dysphagia associated with LD and dementia and continued need for training of staff supporting adults with LD and dementia with regards to the risks associated with this is required | Thank you for your comment. The Scoping Group agreed that training needs around all aspects of supporting older people living with learning disabilities is covered by point 6 of the key area covered (1.3 of the scope) which states that training of health and social care practitioners will be addressed in the review of evidence. Specifically point 6 reads in the final scope reads "**Training of health and social care practitioners to recognise the assets older people bring to local communities. Also to identify and manage the care needs of older people with learning disabilities, including common health conditions and** |

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| | | | | | | **communication and support needs."** |
| 2.07 | SH | Lancashire Care NHS Foundation Trust | General | General | Assessment and development and review of individualised guidelines by specifically trained S&LT to manage risk of choking as a result of dysphagia in adults with LD and dementia and other age related conditions that might lead to the development of dysphagia is essential. | Thank you for your comment. The suggestion you make is a possible area in which the Guideline Committee may develop recommendations if supporting evidence is located. The scoping group therefore agreed that no changes were needed to the final scope in light of your comment. |
| 2.08 | SH | Lancashire Care NHS Foundation Trust | General | General | Acknowledgment of difficulty of diagnostic overshadowing making diagnosis of dementia difficult for adults with LD, hence need for objective pre-morbid baseline assessment and/or knowledge of skills and abilities to aid with diagnosis. | Thank you for your suggestion. We agree that diagnostic overshadowing is a particular problem in this context and have therefore made a clearer reference to it in the context section of the final scope. |
| 2.09 | SH | Lancashire Care NHS Foundation Trust | General | General | Access to assessment of dementia and medication and other interventions for dementia is essential and should be available for adults with LD who are thought to be at risk of developing or have been diagnosed with dementia, (respectively). | Thank you for your comment. The suggestion you make is a possible area in which the Guideline Committee may develop recommendations if supporting evidence is located. The scoping group therefore agreed that no changes were needed to the final scope in light of your comment. |
| 3.01 | SH | NHS England | General | General | . I wish to confirm that NHS England has no substantive comments to make regarding this consultation | Thank you, we have noted this. |
| 13.01 | SH | Optical Confederation | General | General | Following several recent consultations regarding health and social care support for older people, we welcome the opportunity to feed into this consultation on care and support for older people with learning disabilities. 1 in 5 of those aged 75 and older and 1 in 2 of those over 90 experience sight problems ranging from easily correctible refractive error, to preventable or treatable conditions to irreversible sight threatening disorders (**Access Economics. 2009. Future Sight Loss (1): The economic impact of partial sight and blindness in the UK adult population, 1.1 Definitions of Partial Sight and Blindness, p.3**).<br><br>These risks are magnified for people with learning disabilities, who are at 10 times greater risk of serious sight problems and visual | Thank you for your comment and for all the information you provide. Older people with learning disabilities and sight loss are covered by the scope and if relevant evidence is located then the Guideline Committee will consider developing specific recommendations around the issues you highlight.<br><br>Thank you for the references you have provided. These will be passed to the review team and |

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| | | | | | impairments than people without learning disabilities. These issues often arise at a younger age in people learning disabilities than the rest of the population; approximately 14% of people with learning disabilities over age 50 are diagnosed as visually impaired or blind, and a further 56% experience refractive error (**Emerson and Roberson. 2011.; commissioned by RNIB and SeeAbility, accessible at: http://www.rnib.org.uk/knowledge-and-research-hub/research-reports/prevention-sight-loss/prevalence-VI-learning-disabilities**).<br><br>Further, recent research into the links between social and income inequality and sight loss affecting older people indicate that the most disadvantaged older adults are at 80% greater risk of developing severe visual impairment compared to the least disadvantaged (**Nazroo et al. 2015.; accessible at: http://www.pocklington-trust.org.uk/researchandknowledge/publications/changes-in-vision-in-older-people-causes-and-impact.htm**). Given that older people with learning disabilities are at increased risk of social inequality and marginalisation, as noted in this consultation document, these risks are exacerbated. | considered for inclusion in the systematic review of evidence underpinning the guideline. |
| 12.01 | SH | Royal College of Nursing | General | General | The Royal College of Nursing (RCN) welcomes proposals to develop this guideline. It is timely. The draft scope seems comprehensive. | Thank you for your support. |
| 12.02 | SH | Royal College of Nursing | General | General | We need to start thinking about people's chronological age not just their biological age. | Thank you for your comment. The scoping group and almost all stakeholders contributing to the scope consultation, supported the decision to avoid using a chronological age cut off for defining older people. |
| 10.01 | SH | Royal Pharmaceutical Society | General | General | We note that clinical treatment for, and the management of, medical conditions is excluded from this scope. However, we believe that medicines must be within the scope of this guideline as they are a vital part of caring for a person with learning disabilities, particularly if they have other long term conditions. The use of medicines need to be embedded into all guidance around | Thank you for you comment. Please be assured that excluding clinical treatment and management of medical conditions from the scope does not imply that medicines optimisation will also be excluded. If evidence is located about medicines optimisation with the context of care and support |

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| | | | | | social care and not seen as a separate issue. We also believe that medicine reviews should become an integral part of care pathways to ensure that people are only taking those medicines that are appropriate for them. | for older people with learning disabilities then the Guideline Committee will consider developing recommendations on this basis. |
| 9.01 | SH | SeeAbility | General | General | SeeAbility understands the rationale for not setting a lower age limit on who the guideline will cover as this will only be arbitrary given the variation in age related health issues that people with learning disabilities face. It is important that the full guideline is very clear that younger adults exhibiting older age related health and care needs should still have choice and control over their living environment and may still wish to be living with their peer age group.<br><br>For example, in our experience, middle aged adults with learning disabilities and sight loss are sometimes being placed with much older adults with dementia or other complex health needs just because these are the only services commissioners have available. It is vital that commissioners are encouraged to develop services for younger people that are able to provide support for age related health issues – this is likely not just a concern for those with learning disabilities but other conditions such as Parkinson's and dementia that are presenting in younger and younger people. | Thank you for your comment and support for avoiding an age cut off within this guideline. We agree about the importance of ensuring age-appropriate services which is why this has been included under key area 7 of section 1.3 of the scope. This key area describes how service planning and organisation for older people with learning disabilities will be covered, including age-appropriate service planning and configuration and types of age-appropriate service provision and accommodation. |
| 9.07 | SH | SeeAbility | General | General | There is also evidence that people with learning disabilities are not accessing the care they need and may present late with eye care symptoms. Rates of diabetes are higher in the population with learning disabilities but there is evidence that diabetic screening – key to preventing sight loss due to diabetes – is failing to adequately monitor people with learning disabilities. (**Pilling, R. (2015), Screening for diabetic retinopathy in adults with learning disability: current uptake and adjustments to** | Thank you for your comment. Older people with learning disabilities who experience diabetes and/ or sight loss are included within scope, just as all older people with learning disabilities are. In addition, screening for all health and social care needs (including diabetes and sight loss) are included in scope, specifically in key area 3 about interventions to support access and referral to health, social care and housing support services, |

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| | | | | | **facilitate equality of access. British Journal of Learning Disabilities, 43: 62–65.)**<br><br>If there is poor access to eye care, subsequent visual impairment may compound pre-existing disability in some people with learning disabilities (**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**).<br><br>It may also increase the risk of self-injurious behaviour (**De Winter C, et al. Physical conditions and challenging behaviour in people with intellectual disability: a systematic review. J Intellect Disabil Res. 2011 Jul;55(7):675-98)**. | including screening, health checks and advocacy. |
| 4.01 | SH | The Royal College of General Practitioners | General | General | My working definition of a person with LD is someone who will not progress beyond the abilities of a 7 year old "normal" person.<br><br>There are considerable differences in the needs and requirements between people with severe LD and those with mild/moderate LD.<br><br>Age can be a useful criterion as needs will vary, and health will deteriorate physically and mentally with age. Perhaps 18-25, 26-40 and over 40.<br><br>Concomitant physical disability is important in terms of special senses – vision, hearing and effective aids; movement/spasticity and co-ordination in terms of the opportunity for work and general mobility by personal, public or private transport.<br><br>Information and a regular review of the LD community and their needs is only then possible. Previously there was a District Handicap Team and a Handicap register kept by the LA. This was | Thank you for your comment. The scoping group and almost all stakeholders contributing to the scope consultation, supported the decision to avoid using a chronological age cut off for defining older people so the final scope still reflects that approach. We agree with you that within our population of interest, people's needs will vary and this is reflected in the language of the scope, which promotes person centred care and prioritises person centred outcomes.<br><br>The other issues you raise, for example about the configuration of care and support services, comorbid conditions and the provision of practical and emotional support (for example relating to life changes) are all covered within the scope. The review of evidence will therefore seek evidence in these areas and if it is located the Guideline |

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| | | | | | computerised and individuals reviewed regularly and their need/achievement/sickness record updated and services provided appropriately.<br>Ideally this is the best way to achieve sensitive care and support with all agencies having access to the register. The average GP will have 5-6 patients with LD yet the GP service may be the best place to ensure regular updates of the changing needs of people with LD and their carers.<br>A GPwSI covering a practice population of 50,000 people may be a possible solution. Similar models exist for cystic fibrosis.<br><br>There is a difficult area around sex, reproduction and the bringing up of children.<br><br>LD and its best management is an area little researched and this needs to be addressed but with real problems around consent and ethics. | Committee will consider developing recommendations on these issues.<br><br>Where we identify gaps in research evidence on care and support for older people, the Guideline Committee will consider whether to develop recommendations for research in that particular area. |
| 9.06 | SH | SeeAbility | 5-6 | General | Page 5 - "What is the effectiveness and cost effectiveness of providing advice and training for older people with learning disabilities"<br>Page 6 - "What is the effectiveness and cose effectiveness of interventions to improve access and referral to health and social care services for people with learning disabilities"<br><br>We have developed easy read material for people with learning disabilities and their supporters to provide information about their sight, and for optometrists to provide information on the results of the eye test. We also provide training for health and social care staff. Should NICE wish to feature good practice and evidence on interventions that support uptake of eye care amongst people with | Thank you for your comment and for your offer of good practice examples, which we will share with the Guideline Committee and may consider as part of our implementation work. |

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| | | | | | learning disabilities we have a number of pieces of work which could feature. .<br><br>Most recently, we have been working with the Local Optical Committee Support Unit (LOCSU) to provide enhanced optometric support for people with learning disabilities in a number of local areas and the findings of these projects include identifying new eye health concerns in many individuals. For example, in the LOCSU project in the Kensington and Chelsea, Hammersmith and Fulham, and Westminster triborough area a third of patients had a new eye health issue identified from their sight tests, and 6 in 10 received new or replacement glasses. For 50% of patients the date of their previous sight test was more than 2 years ago or unknown. Many of the people who had their sight tested were over 60 years old, and significantly some 10% of patients were referred on for cataract surgery, with smaller numbers being referred on for glaucoma or diabetes-related eye health concerns.<br><br>The aim of SeeAbiilty's public health programme of work has been to address the issues identified in a number of pieces of research regarding why there are issues around uptake and access to eye care. For example:<br><br>Reporting of sight problems is often symptom led (**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.)** so this puts people with communication difficulties at major risk of not getting the eye care they need. | Thank you for this information and for the journal articles you have cited. The review team will be able to consider these for inclusion in the review of evidence underpinning the guideline. |

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| | | | | | Behaviour may be wrongly attributed to the diagnosis of a learning disability, rather than a sight problem (known as "diagnostic overshadowing"). Professionals who know the person best may think they can see perfectly well and yet the person's sight may be at major risk **(Newsam, H et al. 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 Impact Factor & Information).**<br><br>Even dedicated schemes to ensure people with learning disabilities get annual health checks, has found many people were not being told about eye care.(**Codling, M. 'Eye Know': translating needs from annual health checks for people with learning disabilities to demand. British Journal of Learning Disabilities, 41(1), 2013, pp.45-50.)** | |
| 9.04 | SH | SeeAbility | 3-4 | General | The guideline should consider and cross reference any guidance on age discrimination and ensuring equality of access to services irrespective of age.<br><br>There is 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. | Thank you for your comment. There will be a number of NICE guidelines relevant to this one and we will definitely refer across where this is appropriate.<br><br>The scoping group is confident that this issue will be addressed because one of the key areas of the scope is training of health and social care practitioners to identify and manage the care needs of older people with learning disabilities, including common health conditions and communication and support needs. If the evidence review locates research specifically about rehabilitation services for older people with learning disabilities and visual impairment then |

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| | | | | | | the Guideline Committee will consider developing recommendations on this issue. |
| 11.09 | SH | British Institute of Learning Disabilities | 1 | 18 | What is meant by "carer" is this paid staff? Family members? | Thank you for your question. The term 'carer' is always used to refer to someone who helps another person (usually a relative or friend) in their day-to-day life. This is not the same as someone (for example a practitioner) who provides care professionally or through a voluntary organisation. Where the term 'carer' is used in the final guideline, a glossary definition will be provided. |
| 11.10 | SH | British Institute of Learning Disabilities | 1 | 18 | Add advocates | Thank you for your suggestion. We agree with you and have therefore added 'advocates' to line 20, page 1 of the final scope 'it will also be relevant to'. |
| 11.11 | SH | British Institute of Learning Disabilities | 1 | 19 | Needs to say health and social care commissioners | Thank you for your comment. We agree with your suggestion and have changed the final scope accordingly. We have also referenced commissioners of housing support because this is in line with the remit. |
| 6.03 | SH | Care and Repair England | 1 | 26 | Add **housing and environmental health services** to the list | Thank you for your suggestion. Housing practitioners are already included as a primary audience ("who the guideline is for"). The scoping group agreed that adding 'housing and environmental services' to the 'it will also be relevant to' seems unnecessary and broadens the scope of the guideline too far. |
| 9.02 | SH | SeeAbility | 2 general | General | The focus of the guideline needs to ensure it comprehensively covers carers of older people with learning disabilities.<br><br>Although the document, in its discussion and analysis, recognises that carers of older people with learning disabilities may have been supporting that person without any input from health and social care, and sporadically there are sections of the guideline that | Thank you for your comment. As you have noted, the scope already recognises the crucial importance of carers, families and advocates in relation to older people with learning disabilities. The outcomes listed in section 1.6 include carer related quality of life, which ensures that the review team will the focussed on identifying research that assess the impact of care and |

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| | | | | | make mention of carer needs, the guideline needs to reflect on the whole pathway of support that an older carer may need.<br><br>For example under section 4 – crisis and risk management could focus on evidence towards preventing carer breakdown. | support on carers and families. |
| 11.13 | SH | British Institute of Learning Disabilities | 2 | 25-27 | Add for people to better understand the ageing process and its potential effects on them | Thank you for your comment. The scoping group considered this point to be adequately covered in key area 5 under 'Practical and emotional support (for example, relating to finances, retirement, bereavement *and life changes*). |
| 11.12 | SH | British Institute of Learning Disabilities | 2<br><br>**3?** | 11-12 | Not clear enough go back to wording in the original document | Thank you for highlighting this. We agree that the sentence was not very clear in the draft scope. We have therefore clarified in the final scope as follows: **"Specialist accommodation or accommodation with a housing scheme manager such as extra care housing."** |
| 13.02 | SH | Optical Confederation | 3 | 21-22 | As the 'identification, assessment and regular review of health and social care needs in older people with learning disabilities' is one of the key areas to be covered by the guidance, and given this population's increased risks to sight and eye health issues, we feel strongly that the importance of regular sight checks should fall within the scope of this guidance and should be highlighted to health and social care providers and practitioners who may not otherwise understand the full benefits of regular sight checks. Regular sight tests and correction of any refractive error support communication and social interaction, and offer the opportunity to prevent and treat eye health conditions before they become sight threatening. Regular sight tests also support overall health and management of conditions such as diabetes and high blood pressure, and help to prevent falls and hip fractures, all of which are more prevalent among older people and people with learning disabilities owing to lifestyle factors (**Pilling, R. 2015. Screening for diabetic retinopathy in adults with learning disability:** | Thank you for your comment. The scoping group understood and acknowledged the importance of regular sight checks for this population. However, hearing, dental care, and many other health-related issues were also referenced and the group felt that they felt were of equal importance. The description in Key Area 1 has been kept deliberately broad so as not to highlight one particular issue at the expense of other equally important areas.<br>In line with yours and other stakeholder comments, the group decided that these issues should be flagged in the 'Key Facts and Figures' section of the scope. "Sensory impairment (including hearing and visual) and dental problems" are now highlighted as particular health-related problems which are more prevalent |

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| | | | | | **current uptake and adjustments to facilitate equality of access. British Journal of Learning Disabilities, 43:62–65; Douglas et al. 2006. Network 1000**).<br><br>Health and social care providers and carers may need additional education and support to ensure that changes in vision are noted and referred on for appropriate care as early as possible, particularly given the high prevalence of sight problems and the fact that people with learning disabilities may be less able to communicate such changes. | in this population. |
| 14.01 | SH | Real Life Options | 3 | 8 | There needs to be a definition of supported living, the examples shown are of very specific types of provision and require other definitions, or 'such as' should be replace with 'including' | Thank you for your comment. The scoping group agreed that the phrase 'supported living' risked being misinterpreted. 'Supported living' is now linked to the Think Local Act Person definition in order to clarify its intended meaning. The wording under 'Community Settings' has been amended to "Supported living, *including* KeyRing Network and Shared Lives schemes" as per your suggestion. |
| 6.04 | SH | Care and Repair England | 3 | 21 | Change to health, social care **and housing** | Thank you for your comment. The scoping group agreed that housing was an extremely important issue for this population. The group considered housing (insofar as planning for future housing, adaptations and equipment, and the quality of housing environments) to be covered by the phrase 'care and support' in the guideline's title, and made several changes throughout the scope to reinforce this. An explanatory note about care and support in the context of the Care Act 2014 (which connects the suitability of living accommodation to a person's well-being) now appears under 'Topic' in the scope. Key area 1 now refers to the 'care and support needs' of older people with learning disabilities as opposed to their 'health and social care needs', which |

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| | | | | | | could risk being more narrowly interpreted. |
| 6.05 | SH | Care and Repair England | 3 | 23 | Change to health, **social care and housing** | The scoping group considered that 'carer's needs' adequately covered 'health, social care and housing' needs without explicitly stating them. A sentence has been added under 'Topic' which explains that "In line with the Care Act 2014 the guideline covers health and health-related provision (including housing), and other care and support". |
| 9.03 | SH | SeeAbility | 3 | 26 | We think this section on information, advice and training should also include identification of changes in health and social care needs to promote referral into support. For example do older adults with learning disabilities and older carers understand eligibility criteria for appropriate social care support and their rights to access that support if eligible? This is particularly important thanks to the recent eligibility changes under the Care Act 2014. It would be helpful for older adults and carers to be made aware of the higher likelihood that people with learning disabilities will have sight problems (see next sections), be encouraged to report changes in vision and have information that regular sight tests are recommended for different age groups to identify issues and take any action needed. | Thank you for your comment. The scoping group considered that referral and identification of changes in health and social care needs were adequately covered by key area 3: "Interventions to support access and referral to health, social care and housing support services, including screening, health checks and advocacy (including self-advocacy)." |
| 9.05 | SH | SeeAbility | 4 | General | general comments on "interventions to support access and referral to health services" and "training of health and social care staff to identify and manage the care needs of older people with learning disabilities":<br><br>It is vital that this section reflects eye care and vision in the interventions listed when the draft guideline is published. We would urge that the guideline at least promotes: | Thank you for your comment.<br>The scoping group understood and acknowledged the importance of regular sight checks for this population. However, hearing checks, dental care, and many other health-related issues were also regarded as equally relevant. Higher prevalence, discriminatory judgement and (in)ability to self-report problems are factors which need consideration across the health and social care spectrum; the scoping group did not think it was |

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| | | | | | • The need for regular sight tests (these are distinct from annual health checks, which do not check on sight)<br>• The need for health and social care staff to be aware of vision and the need to make referrals for sight tests if they suspect a change in vision.<br><br>It is notable under Key Facts and Figures (Section 3.1) that there is no note of the prevalence of sight loss amongst older adults with learning disabilities and we urge NICE to ensure this is rectified. There is a considerable amount of research on this.<br><br>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 http://www.rnib.org.uk/knowledge-and-research-hub/research-reports/prevention-sight-loss/prevalence-VI-learning-disabilities). 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 visually impaired or blind, and a further 56% have refractive error), as will the risk of age related macular degeneration, cataracts and other eye health conditions.<br><br>Many of these sight problems are preventable and treatable but will be dependent on if the person themselves is aware of them and can self-report on their problems, and that carers and staff supporting the individual are alert to the likelihood of sight problems. For example, cataracts are one of the most common | appropriate to highlight sight loss over and above any other health issues, but eye care is of course covered by the phrase 'health checks' (as opposed to GP check-up).<br><br>In line with yours and other stakeholder comments, and in light of the information you have provided, the scoping group agreed that 'sensory impairment' should be referenced in the 'Key Facts and Figures' section of the scope. On page 12 of the final scope, sensory impairment (including hearing and visual) and dental problems are now highlighted as particular health-related problems, which are more likely to affect this population. |

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| | | | | | reversible causes of visual loss in patients with a learning disability (see: http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1857461/). 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.<br><br>It is vital that people with learning disabilities are referred on to health care the same as people without learning disabilities – so there is no discriminatory judgements made if the person doesn't read, work or drive, for example. Proper consideration of capacity and consent issues and Best Interest meetings are also important to ensure that barriers to health interventions are overcome. | |
| 11.14 | SH | British Institute of Learning Disabilities | 4 | 1-3 | Needs to add and the reasonable adjustments that mainstream services need to make to effectively support older people with a learning disability | The scoping group agreed that reasonable adjustments are likely to be covered in the guideline and do not need to explicitly stated in the scope. |
| 13.07 | SH | Optical Confederation | 4 | 24-26 | Most sight care relies on self-reporting of symptoms, yet people with learning disabilities may struggle to communicate changes in their vision. We know that vision problems are often overlooked and may not be well understood by front line staff, and in the case of people with learning disabilities may be confused with other aspects of their diagnosis (which is known as 'diagnostic overshadowing'). We therefore believe that training on recognising changes in vision will be needed to correctly and swiftly identify vision loss among this population. | The group agreed that diagnostic overshadowing was an important consideration. Diagnostic overshadowing will now be referenced in the context section of the final scope - not just in relation to sight loss, but a range of other conditions too. DRC's report into health inequalities will now be referenced in this section as a way to acknowledge the risks of diagnostic overshadowing for this population. DRC's formal investigation into physical health inequalities experienced by people with LD and/or MH conditions"(Closing the Gap). |
| 13.04 | SH | Optical Confederation | 4 | 8-9 | We are aware of numerous instances in which people's essential functional aids, such as spectacles and hearing aids, are left behind in the event of a health emergency or other crisis. We therefore suggest that the guidance prompt carers and support workers to double check that these aids are taken with them in the | Thank you for your comment. The scoping group recognised the importance of ensuring that older people with learning disabilities retain their functional aids at a time of crisis. If evidence on this topic is located by the evidence review on |

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| | | | | | event of a crisis as their loss may have an adverse effect on people's ability to communicate. Information on the person's visual and eye care needs, including their usual aids, must be included in 'health passports'. Commissioning of the LOCSU Community Eye Care for Adults & Young People with Learning Disabilities Pathway is essential to ensure adequate training and funding for this to be actioned. | crisis management, and contingency and future planning (for example) the Guideline Committee can consider developing recommendation on this issue. |
| 6.06 | SH | Care and Repair England | 4 | 1 | Change to health, social care **and housing** | Thank you for your comment. Key area 3 has now been amended to: "Interventions to support access and referral to health, social care and housing-support services, including screening, health checks and advocacy (including self-advocacy)." As the scope covers planning for future housing and suitability of accommodation, as opposed to effectiveness of housing provision itself, 'housing-support' was deemed more appropriate than 'housing'. |
| 13.03 | SH | Optical Confederation | 4 | 2 | The guidance must make clear that health checks provided by GPs do not include the full range of diagnostic tests performed as part of a sight test carried out by a registered optometrist. In most cases, GPs do not have the equipment or specialist knowledge necessary to monitory health conditions such as diabetes by examining the eye. There is evidence that even among those who do take up regular health checks, eye health is often not adequately addressed (**Codling, M. 2013. 'Eye Know': translating needs from annual health checks for people with learning disabilities to demand. British Journal of Learning Disabilities, 41(1):45-50**).<br><br>Recognising the need to improve access to good eye care services, the Local Optical Committee Support Unit (LOCSU) has developed a new Community Eye Care Pathway for Adults and Young People with Learning Disabilities. The pathway, which can be viewed here: http://www.locsu.co.uk/community-services-pathways/community-eye-care-pathway-for-adults-and-young-pe, | Thank you for your comment and for providing this information. The scoping group thought that 'eye sight checks' were adequately covered by 'health checks' as the scope does not state that they are specifically GP health checks.<br><br>In line with yours and other stakeholder comments, the group decided that 'sensory impairment' should be referenced in the 'Key Facts and Figures' section of the scope. "Sensory impairment (including hearing and visual)" is now highlighted as a particular health-related problem which is more prevalent in this population. |

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| | | | | | has been developed in conjunction with two leading charities, Mencap and SeeAbility, to ensure that it reflects the needs of people with learning disabilities and is based on established, successful learning disability services provided by community optometrists in a number of areas in England. The pathway gives Local Optical Committees the basis for a proposal to improve the way eye care for people with learning disabilities is delivered in their local area, including provision for longer appointments, repeat visits and production of extended reports and other written information about the outcome of the eye exam for the patient and other appropriate professionals. | |
| 11.15 | SH | British Institute of Learning Disabilities | 4 | 10 onwards | Need to add something about preventing and reducing social isolation | Thank you for your comment. The scoping group thought that the following bullet of key area 5: 'support to develop and maintain relationships by enabling access to volunteering, social and leisure activities, transport and technology' adequately covered the issue of 'preventing and reducing social isolation'. |
| 13.05 | SH | Optical Confederation | 4 | 12 | We are aware that aids such as spectacles and hearing aids are sometimes missed when people are assisted with dressing, for example in care homes. As people with learning disabilities may be less able to self-report such omissions, we recommend that the key role of such aids in supporting communication and independence be highlighted in the guidance. Again, information on sensory needs and visual aids must be included in 'health passports', which is greatly supported by commissioning of the LOCSU Community Eye Care for Adults & Young People with Learning Disabilities Pathway. | Thank you for your comment. The scoping group recognised the importance of ensuring older people with learning disabilities retain their functional aids. If evidence on this topic is located by the review the Guideline Committee will be able to make recommendations accordingly. |
| 13.06 | SH | Optical Confederation | 4 | 13 | Regular sight testing and uptake of enhanced schemes such as diabetic eye screening carried out in high street optical practices – many of which are open 7 days per week – are a convenient, effective and cost effective way to support management of chronic health conditions. | Thank you for your comment and for passing on this information. |
| 6.07 | SH | Care and Repair | 4 | 20 | Add housing related support **including repairs and adaptations to the home** | Thank you for your comment. The scoping group agreed that your suggested edit was an important |

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| | | England | | | | one. This bullet point now reads: "Housing-related support including, equipment, adaptations and assistive technology." |
| 6.08 | SH | Care and Repair England | 4 | 24 | Change to health, social care **and housing staff** | Thank you for your comment. The scoping group agreed that training of 'housing staff' is beyond NICE's remit and should not be added to this key area as suggested. Other edits have been made throughout the scope in relation to housing to help clarify exactly to what extent housing is covered. |
| 5.01 | SH | National Development Team for Inclusion | 4 | 24 | Need to add in something about training of health and care staff to recognise the assets older people with learning disabilities can bring to their local communities. It reads as rather needs based at the moment. | Thank you for your comment and for raising this important point. Key area 6 has now been amended to include training of health and social care staff to recognise the assets older people with learning disabilities can bring to their local communities. |
| 8.01 | SH | Tees, Esk and Wear Valleys NHS Foundation Trust | 4 | 31 | This intention is inconsistent with that on Page 2 Line 15 in terms of cut-off age. | Thank you for your comment. The scoping group considered these two issues to be separate. On the one hand, the stated principle of the scope is not to apply an age cut off in terms of the evidence reviewed and the focus of recommendations. And on the other, key area 7 lists the issues of age-appropriate (whatever the age) service planning and configuration. These points are not mutually exclusive. |
| 10.02 | SH | Royal Pharmaceutical Society | 5 | 12+ | The key issues and questions could also include medicines and ask if older people with learning disabilities and their carers are provided with enough information about the medicines and supported to take them. If so, this could enhance their care in general and ensure that they are only taking the medicines that are appropriate for them. | Thank you for your comment. Medicine optimisation and management is covered by the scope and the review questions and will be covered if relevant evidence is located. |

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| 8.02 | SH | Tees, Esk and Wear Valleys NHS Foundation Trust | 5 | 12 | The whole of section 1.5 reads as a repetitive list which could be more succinctly articulated as a table/matrix/diagram | Thank you for your comment. The review questions were formatted in this way because tables and diagrams can cause unnecessary problems for assistive reading technologies. |
| 6.09 | SH | Care and Repair England | 5 | 16 | Change to health, social care **and housing** needs | Thank you for your comment. Review question 1 has now been amended to 'care and support needs'. The scoping group considered that housing was covered by 'care and support' and the Topic section of the scope has been updated to emphasis the role which housing plays in the scope. |
| 6.10 | SH | Care and Repair England | 5 | 18 | Change to health, social care, **housing** and other practitioners | Thank you for your comment. The scoping group did not think it was appropriate to explicitly state 'housing' practitioners for this question. If there is any evidence on the views of housing practitioners this will be covered by 'other practitioners'. |
| 14.02 | SH | Real Life Options | 5 and general | 22 And general | We are puzzled by the question 'what is the effectiveness and cost effectiveness' – we are not convinced this is the best measure. This should be based on outcomes for the individuals. | Thank you for your comment. Please be assured that we have a range of person-focused outcomes to measure effectiveness (in addition to service outcomes) which are listed in the scope. The economist working on the guideline will need to consider cost-effectiveness data as NICE strive to create guidelines based on the best available evidence (including cost-effectiveness). Within social care research costs are usually offset against harms or benefits to the individuals who are receiving the service or intervention. |
| 14.03 | SH | Real Life Options | 5 | 23 | We are unclear what 'training' refers to here? We feel that this clause should focus on information and advice. | Thank you for your comment. Training is intended to mean any programme of teaching which will empower the older person with learning disabilities. The scoping group felt that it was important to keep this in. |
| 6.11 | SH | Care and | 5 | 26 | Change to health, social care, **housing** and other practitioners | Thank you for your suggestion. The scoping |

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| | | Repair England | | | | group did not think it was appropriate to explicitly state 'housing' practitioners for this question. If there is any evidence on the views of housing practitioners this will be covered by 'other practitioners'. |
| 13.08 | SH | Optical Confederation | 6 | 7-9 | Community optical practices offer effective and cost effective interventions via GOS, locally commissioned Minor Eye Condition Service (MECS) and screening programs such as diabetic retinopathy screening. All adults over 60 are entitled to free eye tests and many people with learning disabilities will have other entitlements that enable them to access GOS free of charge, whilst MECS and other screening services are publicly-funded and fee at the point of use. Uptake of these interventions reduces the cost and time burden on hospital ophthalmology and emergency departments as the majority of acute eye conditions are urgent rather than serious, and most screening, monitoring and follow up can be done more cheaply but to the same standard by properly qualified community optometrists. Correct recording of the outcomes of these exams – via both 'health passports' and extended reports where appropriate – is essential to ensure that people with learning disabilities receive all the necessary aftercare and ongoing support. | Thank you for your comment and for providing this information.<br>Information sharing practices – such as the hospital passport – will be covered by this review question. |
| 14.04 | SH | Real Life Options | 6 | 7 | We feel this clause, in order to be strong enough to ensure people have access to services, needs to illustrate the broad range of services that may be important, from chiropody to diagnosis of a potentially terminal illness and end of life care. | Thank you for your comment. The scoping group considered the wording of the question to be sufficiently open to cover the breadth of services you have referenced. Giving specific examples would risk overlooking others, so it was decided that this part of the scope should remain unchanged. |
| 6.12 | SH | Care and Repair England | 6 | 8 | Change to health, social care **and housing** services | Thank you for your suggestion. Review question 5 has now been amended to: What is the effectiveness and cost effectiveness of interventions or approaches to improve access and referral to health, social care and housing support services for older people with learning |

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| | | | | | | disabilities? |
| 6.13 | SH | Care and Repair England | 6 | 12 | Change to health, social care **and housing** services | Thank you for your suggestion. The scoping agreed to include housing support services in review question 5. |
| 6.14 | SH | Care and Repair England | 6 | 15 | Change to health, social care **and housing** | Thank you for your suggestion. The scoping agreed to include housing support services in review question 5. |
| 14.05 | SH | Real Life Options | 7 | 7 | Planning for end of life care should also be included. | Thank you for your comment. Planning for end-of-life care will be covered by this review question. |
| 10.03 | SH | Royal Pharmaceutical Society | 7 | 7 | End of life care often involves the use of medicines so should be part of the question around this. | Thank you for your comment. Clinical treatment is beyond the remit of the scope. However if there is any information about managing medicines at the end of life it will be included under this review question and the Guideline Committee will be able to consider developing recommendations on this issue. |
| 14.06 | SH | Real Life Options | 7 | 15 | Supported living in not qualified here and is therefore inconsistent with 3, 8 | Thank you for your comment. This review question applies to all older people with learning disabilities and their carers regardless of their living situation. |
| 6.15 | SH | Care and Repair England | 7 | 16 | Change to care, support **and housing** practitioners | Thank you for your comment. The 'Topic' section of the scope has been amended to include an explanation of care and support including housing support in line with the Care Act 2014. The importance of providing support for housing has been emphasized throughout the scope. |
| 14.07 | SH | Real Life Options | 7 | 16 | Replace 'available' with 'required' | Thank you for your comment. The review question is worded in this way because it aims to find studies which evaluate the impact of all existing training. To use 'required' would be making a normative value judgement. |
| 14.08 | SH | Real Life Options | 7 | 17 | How is the 'impact' of training to be measured and what training is this referring to? | Thank you for your comment. Training refers to any intervention aimed at improving knowledge |

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| | | | | | | and practice among all practitioners offering care and support to older people with learning disabilities.<br>Impact will be measured through evaluating older people with learning disabilities' or relevant service outcomes which can be causally linked to training interventions. Ideally this evidence would be provided by randomised controlled trials which would have a control group (not receiving the training intervention), but more realistically the evidence will be located in studies with a before and after design. |
| 6.16 | SH | Care and Repair England | 7 | 18 | Change to care, support **and housing** practitioners | Thank you for your comment. The scoping group did not consider training of housing practitioners to be within NICE's remit so this question has not been amended. |
| 5.02 | SH | National Development Team for Inclusion | 7 | 23 | I think it is probably implicit within this section – but within person centred outcomes, there is a need to be explicit about support for planning for the future – both for older people with learning disabilities themselves, and family carers of older people with learning disabilities. | Thank you for your comment. The scoping group did not see 'planning for the future' as an outcome measure *per se.* Care planning is covered in the scope, and satisfaction with services and independence, choice and control over daily life were seen as adequate outcome measures to capture it. |
| 13.09 | SH | Optical Confederation | 7 | 24 | Community optical services have an important role to play in supporting older people with learning disabilities to retain the maximum amount of independence, choice and control over daily life. Professionals and carers may not always have full insight into the importance of good sight for people who may not read, work or drive. However, communication and social inclusion are important aspects of valuing and supporting people with learning disabilities to lead independent lives; both depend greatly on sensory functioning – at a minimum through either vision or hearing, though ideally through both. In order to empower people with learning disabilities and their carers as active health advocates, sensory conditions and necessary aids and accommodations should be | Thank you for your comment. The scoping group was confident that the scope covers information sharing practices. If evidence on 'health passports' or community optical services is located the Guideline Committee will be able to consider developing recommendations on this issue. |

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| | | | | | recorded in 'health passports' with details provided in extended reports where appropriate.<br><br>Moreover, the variety of community optical services offers an opportunity for people to exercise real choice and control in their care and treatment, selecting the practice with the approach and accommodations that best suit their needs. | |
| 13.10 | SH | Optical Confederation | 7 | 29 | It is important that choice and continuity of care be preserved. For example, if people with learning disabilities enter care homes, staff should offer them the option of continuing to see their regular eye health practitioner if they wish and support them in making the necessary arrangements. | Thank you for your comment and your support for these outcomes. |
| 6.17 | SH | Care and Repair England | 7 | 30 | Change to health, social care **and housing** related quality of life | Thank you for your comment. Health and social care (including cleanliness and comfort of accommodation) and related quality of life is covered in ASCOT, so the scoping group agreed that housing-related quality of life did not need to be added to outcomes. |
| 5.03 | SH | National Development Team for Inclusion | 8 | 2 | Should this include reablement/rehabilitation services? | Thank you for your comment. Secondary, primary and community health and social care services includes reablement and rehabilitation services so there is no need to amend this. |
| 13.11 | SH | Optical Confederation | 8 | 2 | Optometry, despite being one of the four primary care professions, is sometimes overlooked by health and social care professionals. If use of primary care services is a key outcome of the proposed guidance, we believe that the value of healthy vision and the role of community optical services in supporting this will need to be highlighted. | Thank you for your comment, we will consider this when conducting the review of evidence which underpins the guideline development process. |
| 14.09 | SH | Real Life Options | 8 | 3 | 'Housing support' has not been previously referred to – is this 'supported housing' or something new? | Thank you for your comment and for pointing out this inconsistency in our scope. The phrase 'housing-support' is intended to mean help with planning for future housing, adaptations and housing repairs, as opposed to housing provision. Supported housing has been linked to the Think |

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| | | | | | | Local Act Personal (TLAP) definition, and 'housing support' has now been adapted consistently throughout the scope to illustrate anything relating to the description above. |
| 14.10 | SH | Real Life Options | 11 | general | The Confidential Inquiry into premature deaths of people with learning disabilities by CIPOLD should be a reference http://www.bristol.ac.uk/media-library/sites/cipold/migrated/documents/fullfinalreport.pdf | Thank you for your comment. The scoping group agreed that it was important to reference the Confidential Inquiry into premature deaths of people with learning disabilities. It now appears in the Context section with a particular perspective on the older people population. |
| 13.12 | SH | Optical Confederation | 11 | 13 | We find the omission of vision from this section concerning given the prevalence of sight loss amongst older people with learning disabilities and the multiple ways in which good vision supported by regular eye care can help to maintain physical, mental and social wellbeing. For example, there is evidence that unaddressed sight loss contributes to isolation, loneliness and depression in older adults and significantly increases the risk of falls and hip fractures (**Hodge, Barr and Knox. 2010. Evaluation of emotional support; Douglas et al. 2006. Network 1000**).<br><br>Given that visual impairment has been shown to increase disability in adults with learning disabilities and is associated with increased risk of self-harm, we strongly urge the explicit inclusion of eye care and visual health in the guideline (**Evenhuis, H. M. 2009. Does visual impairment lead to additional disability in adults with intellectual disabilities? Journal of Intellectual Disability Research, 53(1):19-28; De Winter et al. 2011. Physical conditions and challenging behaviour in people with intellectual disability: a systematic review. Journal of Intellectual Disability Research, Jul;55(7):675-98**). | Thank you for your comment. In line with yours and other stakeholder comments, the group decided that 'sensory impairment' should be referenced in the 'Key Facts and Figures' section of the scope. "Sensory impairment (including hearing and visual)" is now highlighted as a particular health-related problem which is more prevalent in this population. |
| 6.18 | SH | Care and Repair | 11 | 16 | Change to social **and related housing** needs | Thank you for your comment. The scoping group agreed to add an explanatory note under 'Topic' |

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| | | England | | | | to situate care and support, including housing, within the frame of the Care Act 2014. |
| 6.20 | SH | Care and Repair England | 12 | 22-26 | We propose that the guidance also considers some of the more complex issues encountered by people with learning disabilities to ensure that the guidance offered in relation to care and support interventions addresses these specifically.<br><br>Our work in 2008 (highlighted in the section above) considered specific support issues for those older people with learning disabilities who hoard, self- neglect and who are carers themselves. We would like the guidance to look at both crisis intervention and prevention strategies for people with these specific needs so adding these issues to the Scope. | Thank you for your comment. Where evidence of sufficient strength is located that relates to these specific issues the Guideline Committee will consider developing related recommendations. These groups - older people with learning disabilities who hoard, self- neglect and who are carers themselves – are in no way excluded from the scope. |
| 6.19 | SH | Care and Repair England | 12 | 10–21 | Many older people with learning disabilities will be living in mainstream housing often with parents or following their parent's death as recognised in the draft Scope. Increasingly they will be home owners and needing help to ensure their home remains suitable as they age.<br><br>It would be helpful to determine the general housing circumstances and tenure of older people with learning disabilities broadening the point about housing and support needs to include practical support with repairs, improvements and adaptations as well as other support to help people to stay in their homes if this is their choice and to prevent an early move to residential care.<br><br>Our report - Living on the Edge - produced in 2008, sets out ways to enable older people with moderate learning disabilities to live independently through housing and other interventions. This includes crisis as well as preventative support and advice and information as well as practical help.<br><br>See http://careandrepair-england.org.uk/wp-content/uploads/2015/01/Living-on-the-Edge-final.pdf | Thank you for your comment. One of the bullets within key area 5 about 'interventions and elements of care and support' has been amended to capture this point: "Housing-related support including, equipment, adaptations and assistive technology." |

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| 13.13 | SH | Optical Confederation | 13 | 21 | As sight loss is often overlooked and may not be well understood by front line staff, we recommend clarifying in plain language that 'sensory impairment' refers to vision and hearing. | Thank you for your comment. The scoping group was confident that 'sensory impairment' was a widely recognised term and did not feel it was necessary to change it. |
| 2.01 | SH | Lancashire Care NHS Foundation Trust | 14 | 6 | Future placement and planning for adults with Down's syndrome should take account of high risk of dementia developing in later life and ensure placements can deliver a capable environment and meet needs throughout life including end of life. For example ensuring that the placement enviro (at time of placement in 20's 30's etc) can be adapted for loss of mobility requiring hoists, access to disabled shower facilities etc in later life to prevent need for move once dementia progresses. | Thank you for your comment. Suitability of living accommodation and adaptations and planning for future housing are covered in the scope. The high prevalence of dementia for people with Down's syndrome is referenced in the Key Facts & Figures section. |
| 2.03 | SH | Lancashire Care NHS Foundation Trust | 16 | 22 | The importance of a person with LD and dementia remaining in their home, particularly where the person with LD is living in shared lives or supported living or residential services for adults with LD with LD/older adult services supporting the person through to end of life is important. Nursing home(s) as a placement possibility for adults with LD and dementia should only be considered as a last resort. (see Royal college/BPS guidance on commissioning in appendix of 2015 good practice guidance for adults with LD and dementia) | Thank you for your comment and for providing this useful reference. Where evidence of sufficient strength is located that relates to these specific issues the Guideline Committee will consider developing related recommendations. |
| 2.04 | SH | Lancashire Care NHS Foundation Trust | 16 | 22 | Where a person with LD and dementia cannot be supported in their own home (e.g. family home) a supported living or residential placement for adults with LD should be considered rather than nursing home. (see Royal college/BPS guidance on commissioning in appendix of 2015 good practice guidance for adults with LD and dementia) | Thank you for your comment. Where evidence of sufficient strength is located that relates to these specific issues the Guideline Committee will consider developing related recommendations. |
| 2.05 | SH | Lancashire Care NHS Foundation Trust | 16 | 25 | Joint working between district nursing and LDS is important to ensure adults with LD and dementia are not admitted to hospital unnecessarily leading to further deterioration of their dementia. However, medical care should be available (including inpatient care) where it is required to treat and discharge the person asap back to their familiar environment. | Thank you for your comment. The scoping group anticipate that there will be evidence about joint working and admission avoidance. Where evidence of sufficient strength is located the Guideline Committee will consider developing related recommendations. |
| 2.02 | SH | Lancashire Care NHS | 16 | 28 | This includes access to prospective screening for adults with Down's syndrome to carry out baseline assessment to aid | Thank you for your comment. The scope references the high prevalence of dementia in |

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| | | Foundation Trust | | | diagnosis of dementia in this high risk group. The benefit of prospective screening is less clear for adults with LD as is the benefit of repeat screening for any group where concerns/changes have not been highlighted/observed by carers. | people with Down's syndrome under key facts and figures. Key area 3 of the scope covers: Interventions to support access and referral to health, social care, and housing support services, including screening, health checks and advocacy. |
| 5.04 | SH | National Development Team for Inclusion | 17 | 2 | This is not the most up to date report on JSNAs from IHaL. The most recent report is 2014:<br><br>https://www.improvinghealthandlives.org.uk/securefiles/150907_2016/MjMxMQ__/Joint%20Strategic%20Needs%20Assessments%202014%20%282%29.pdf | Thank you for noticing this. The most up to date report is now referenced. |

**Registered stakeholders**