

Care and support of older people with learning disabilities

Consultation on draft scope – deadline for comments 5pm on 08/09/15

email: opld@nice.nhs.uk

Please note:		Please read the checklist for submitting comments at the end of this form. We cannot accept forms that are not filled in correctly or arrive after the deadline. Developing NICE guidance: how to get involved has a list of possible areas for comment on the draft scope.	
Please also consider:		Is the definition of learning disability used in the scope the most appropriate one? We have not used a specific age limit to define 'older'. Do you: a) think that we should use an age threshold / limit and b) if so what should that age limit / threshold be? What should prompt health and social practitioners to consider whether a person with learning disability is also experiencing issues associated with being an older person?	
Stakeholder organisation (if you are responding as an individual rather than a registered stakeholder please state name here):		<u>Optical Confederation</u>	
Name of commentator (if you are responding as an individual rather than a registered stakeholder please leave blank):		<u>Arielle Nylander</u>	
Comment No.	Page number or 'general' for comments on the whole document	Line number or 'general' for comments on the whole document	Comments Insert each comment in a new row. Do not paste other tables into this table, as your comments could get lost – type directly into this table.

1	General	General	<p>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).</p> <p>These risks are magnified for people with learning disabilities, who are at 10 times greater risk of serious sight problems and visual 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).</p> <p>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.</p>
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2	3	21-22	<p>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: current uptake and adjustments to facilitate equality of access. British Journal of Learning Disabilities, 43:62–65; Douglas et al. 2006. Network 1000).</p> <p>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.</p>
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3	4	2	<p>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 monitor 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).</p> <p>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, 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.</p>
4	4	8-9	<p>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 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.</p>
5	4	12	<p>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.</p>

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6	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.
7	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.
8	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 free 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.
9	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 recorded in ‘health passports’ with details provided in extended reports where appropriate. 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.
10	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.

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11	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.
12	11	13	<p>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).</p> <p>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).</p>
13	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.
14			
15			

Add extra rows if needed

Checklist for submitting comments

- Use this form and submit it as a Word document (not a PDF).
- Include page and line number (not section number) of the text each comment is about.
- Combine all comments from your organisation into 1 response. We cannot accept more than 1 response from each organisation.
- Do not paste other tables into this table – type directly into the table.
- Underline and highlight any confidential information or other material that you do not wish to be made public.
- Do not include medical information about yourself or another person from which you or the person could be identified.
- Spell out any abbreviations you use
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