

National Institute for Health and Care Excellence

Challenging behaviour and learning disabilities

Stakeholder Comments – Draft Guideline

NOTE:

NICE is unable to accept comments from non-registered organisations or individuals. If you wish your comments to be considered but are not a registered stakeholder, please register via the [NICE website](#) or contact the [registered stakeholder organisation](#) that most closely represents your interests and pass your comments to them.

Please fill in both the ‘stakeholder organisation’ and ‘name of commentator’ fields below in order for your comments to be considered.

Stakeholder Organisation:	<u>Optical Confederation</u>
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Name of commentator:	<u>David Craig</u>
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Order number	Document	Section Number	Page Number	Comments
<i>(For internal use only)</i>	Indicate if you are referring to the Full version NICE version or the Appendices	Indicate number or ‘general’ if your comment relates to the whole document	Indicate number or ‘general’ if your comment relates to the whole document	<p>Please insert each new comment in a new row.</p> <p>Please do not paste other tables into this table, as your comments could get lost – type directly into this table.</p>

Example	Full	3.4.6	45	Our comments are as follows
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Proformas that are not correctly submitted as detailed in the example above may be returned to you.

1	Full	General	General	We recognise these guidelines do not cover the treatment and management of co-existing conditions such as sight loss. However sensory impairment is a recognised part of learning disabilities at all ages and age-related impairments occur earlier in PLD than others and so may not be spotted. The presence of sensory impairment impacts not only on a individual’s behaviour but on their ability to communicate with health professionals to achieve effective assessment and treatment of their condition.
2	Full	2.4 d	24	We would like to highlight the prevalence of visual impairment in people with learning disability. There is a link between the severity of the learning disability and the likelihood of visual impairment. <i>(Emerson E, Robertson J. Estimating prevalence of visual impairment among people with learning disabilities in the UK. Lancaster University: Centre for Disability Research, 2011.)</i> There is under detection of visual impairment in all

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				<p>groups of patients with learning disability. (Woodhouse J.M, Ryan B, Davies N, McAvinchey A.(2012) <i>A Clear Vision: Eye Care for Children and Young People in Special Schools in Wales</i>)</p> <p>It is likely that visual impairment is a factor in challenging behaviour and thus it is important to establish not only baseline visual performance in all patients with learning disability but to take into account any changes in vision when assessing the causes of challenging behaviour. (Pilling, R. (2011). <i>The management of visual problems in adult patients who have learning disabilities. Ophthalmic Services Guidance, The Royal College of Ophthalmologists.</i>)</p> <p>Self injury affecting eyes can be the cause of, or result of, eye pathology and should trigger referral for visual assessment by an ophthalmologist or optometrist.</p> <p>The CIPOLD report's finding that 50% of those dying prematurely have visual loss should be noted.</p> <p>It should also be noted that the effectiveness of any therapy requiring visual input to aid communication will be adversely affected unless the visual ability of the patient is taken into account when developing the treatment or assessment plan.</p>
3	Full	2.5.1	26	We ask that acquired visual loss is added to the conditions listed on page 26 line 19 eg retinal detachment or cataract
4	Full	2.5.1	27	Also add the research by Cooper SA, Smiley E, Allan L, Jackson A, Finlayson J, Mantry D, et al. Re the connection between Self-injurious behaviour and visual impairment. (<i>Adults with intellectual disabilities: prevalence, incidence and remission of self-injurious behaviour and related factors. Journal of Intellectual Disability Research 2009;53:200-16</i>).
5	Full	2.5.1	28	No mention is made of 'functional vision assessment' or related tools such as the SeeAbility FVA tool.
6	Full	2.6	33	Children and Families Bill is mentioned and where an Education, Health & Care plan for children and young people with LD is formulated, visual assessment should be included.
7	Full	4.5	77-78	There is no mention of investigation of physical or sensory (visual) problems which may lead to challenging behaviour
8	Full	6.4.2.1	113	Paragraph 6.4 and in particular 6.4.2.1 Team working (page 113) describes professionals who should be part of the assessment team. No mention is made of the eye-care professions; this should be corrected and the LOCSU pathway emphasised as a way of commissioning and delivering these

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				<p>services.</p> <p>The LOCSU Enhanced Service Community Eye Care for Adults & Young People with Learning Disabilities Pathway was launched in 2012 with leading charities, SeeAbility and Mencap. This provides an established pathway to facilitate eye examinations for people with learning disability. This may help prevent some challenging behaviour in the first instance therefore Clinical Commissioning Groups can work with providers in primary care to increase awareness of resources available to this cohort.</p> <p>The need for awareness of and wider use of functional vision assessment tools amongst staff should also be emphasised.</p>
9	Full	7.4	148	<p>Under recommendation 18, add to the point about visual impairment, the requirement for a visual assessment to be made by an ophthalmologist or optometrist, making clear that the service user does not need to be able to read or speak for this to be effective.</p>
10	Full	8.1	150	<p>Paragraph 8.1 outlines the potentially complex causes of BWC and on line 7 physical health is mentioned as one factor to be considered. Line 18 mentions a 'tooth abcess' causing pain as a cause of BWC and lines 25 and 26 professionals included in the assessment team. It would be useful to have acquired visual loss as a cause of BWC mentioned and also for professionals from the eye-care sector, such as optometrists, mentioned in the document.</p>
11	Full	8.2	151	<p>It is likely that sensory deprivation, especially if this is an acquired loss, may add to a defensive response to unusual experiences or abnormal environments, hence testing for sensory impairments should be part of any investigation as to the cause of the challenging behaviour in order to avoid the risk of diagnostic overshadowing. To establish change in visual function it is of course important to establish a baseline visual ability which should be recorded in a patient's notes. This should as far as possible include not only visual acuity, but a full eye examination, visual field and results of a functional visual assessment.</p>
12	Full	8.3	152	<p>Assessment of visual performance and sight testing of all patients at risk of developing challenging behaviour and those who have developed challenging behaviour should be considered to ensure sight loss is not a contributory factor in such behaviour and to facilitate the provision of other therapy and assessment in an appropriate fashion.</p>
13	Full	8.4	159	<p>We would encourage greater training in the importance of sight tests, the ability to carry out functional visual assessment, and recognition of behaviour possibly caused by visual impairment for</p>

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				all health and social care professionals. Such information should also be available for families supporting or caring for people with learning disabilities and challenging behaviour
14	Full	8.5	163	<p>This mentions a graduated approach to investigating the factors which are causing BWC. The risk here is that in not considering the urgent conditions such as corneal ulcers, retinal detachment or acute glaucoma (or indeed other acute health conditions) that by the time these conditions are considered the situation will be too far advanced for there to be successful treatment. Paragraphs 21 page 163 and paragraph 24 on page 164 allude to the need to investigate physical or sensory causes but only when further investigations at paragraph 27 page 166 are suggested is full mention of physical health problem mentioned.</p> <p>Only when certain acute problems have been ruled out then this graduated response should be followed.</p>
15	Full	8.5.2	164	Recommendations 23 and 24: visual assessment, even if a functional one carried out by carer, should occur at the onset of new challenging behaviour rather than waiting to see if controlling strategies work first.
16	Full	8.5.4	166	Recommendation 27: visual assessment, even if a functional one carried out by carer, should occur at the onset of new challenging behaviour rather than waiting to see if controlling strategies work first.
17	Full	9.5.2	194-195	"offer an annual physical health check": it should be made explicit that this contains a sensory assessment, including visual assessment. Refer to guidance that adults would benefit from 2 yearly optometric assessment, and that the same would apply for adults with learning disability, to specify that assessments can take place even if the service user is unable to read or speak. Refer to LOCSU pathway. For children, refer to National Screening Guidance which recommends visual assessment in school at age 4-5 for all children. Refer to "a clear vision" data, and children in focus project
18	Full	9.5.2	195	Para 9.5.2 page 195 recommends the annual health check takes place in whatever the most appropriate setting may be and also in this section mention is made of the importance of the annual health check in raising the proportion of people with LD having regular sight tests. Mention should be made of the availability of domiciliary sight tests as well as the opportunity for commissioning of the LOCSU pathway to support the uptake of sight tests by PwLD.
19	NICE	1.2	22	We note that sensory impairment is mentioned as a contributory factor for challenging behaviour and would like to highlight the prevalence of visual

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				<p>impairment in people with learning disability. People with learning disability are 10 times more likely to have a visual impairment. (<i>Emerson E, Robertson J. Estimating prevalence of visual impairment among people with learning disabilities in the UK. Lancaster University: Centre for Disability Research, 2011.</i>)</p> <p>It is likely that sensory deprivation especially if this is an acquired loss may add to a defensive response to unusual experiences or abnormal environments, hence testing for sensory impairments should be part of any investigation as to the cause of the challenging behaviour in order to avoid the risk of diagnostic overshadowing. To establish change in visual function it is of course important to establish a baseline visual ability which should be recorded in a patient's notes. This should as far as possible include not only visual acuity, but a full eye examination, visual field and results of a functional visual assessment.</p>
20	NICE	1.5.5	26	<p>Assessment of visual performance and sight testing of all patients at risk of developing challenging behaviour and those who have developed challenging behaviour should be considered to ensure sight loss is not a contributory factor in such behaviour and to facilitate the provision of other therapy and assessment in an appropriate fashion</p>
21	NICE	1.5.13	30	<p>It is likely that sensory deprivation especially if this is an acquired loss may add to a defensive response to unusual experiences or abnormal environments, hence testing for sensory impairments should be part of any investigation as to the cause of the challenging behaviour in order to avoid the risk of diagnostic overshadowing. To establish change in visual function it is of course important to establish a baseline visual ability which should be recorded in a patient's notes. This should as far as possible include not only visual acuity, but a full eye examination, visual field and results of a functional visual assessment</p>
22	NICE and FULL	General	General	<p>The Optical Confederation represents the 12,000 optometrists, 6,000 dispensing opticians and 7,000 optical practices in the UK who provide high quality and accessible eye care services to the whole population. The Confederation is a coalition of the five optical representative bodies: the Association of British Dispensing Opticians (ABDO); the Association of Contact Lens Manufacturers (ACLM); the Association of Optometrists (AOP); the Federation of Manufacturing Opticians (FMO) and the Federation of Opticians (FODO). As a Confederation, we work with others to improve eye health for the public good.</p>

Please add extra rows as needed.

Please email this form to: Challengingbehaviour@nice.org.uk

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Closing date: 5pm, 9th February 2015

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