

**Autism in adults
Stakeholder Comments**

Please enter the name of your registered stakeholder organisation below.

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Stakeholder Organisation:	<p>This is a joint response from the Optical Confederation, and the LOC Support Unit. The LOC Support Unit provides quality, practical support to Local and Regional Optical Committees (LOCs/ROCs) in England and Wales to help them to develop, negotiate and implement local objectives in respect of primary ophthalmic services. It is a key interface between the optical, representative bodies and the LOCs/ROCs, facilitating robust lines of communication between the national organisations and the grass roots of the professions.</p> <p>The Optical Confederation represents the 12,000 optometrists, the 6,000 dispensing opticians, and 7,000 optical businesses and 45,000 ancillary staff in the UK, who provide high quality and accessible eye care services to the whole population. The Confederation is a coalition of 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 Ophthalmic and Dispensing Opticians (FODO). As a Confederation, we work with others to improve eye health for the public good.</p>
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Name of commentator:	Ben Cook, Optical Confederation
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Order number <i>(For internal use only)</i>	Document Indicate if you are referring to the Full version or the Appendices	Page Number Number only (do not write the word 'page/pg') . Alternatively write 'general' if your comment relates to the whole document.	Line Number Number only (do not write the word 'line') . See example in cell below	Comments Please insert each new comment in a new row. Please do not paste other tables into this table, as your comments could get lost – type directly into this table.
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Example	Full	16	45	Our comments are as follows
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Proformas that are not correctly submitted as detailed in the line above may be returned to you

1	NICE	general		The Optical Confederation works closely with charities such as SeeAbility who provide specialist services for people with learning disabilities, autism, acquired brain injury, cerebral palsy, and epilepsy. The vast majority of the people supported by SeeAbility also suffer from a visual impairment. Despite being more prevalent among people with learning disabilities, such as autism, visual impairment is all too often undetected in
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such people, adding to their sense of isolation and frustration. It is crucial that support staff working with people with sight loss and autism, are able to use effective and individualised strategies. SeeAbility also regularly hosts training and awareness courses to enable support staff to have a better understanding about autism and sight loss to equip them with the necessary knowledge and tools to support individuals.

We recognise that people with an Autism Spectrum Disorder (ASD) face challenges with:

- Communication
- Invasion of personal space
- Disruption of routine
- Introduction of strangers
- Introduction of equipment

All of these challenges will cause difficulties with normal communication and exam routines¹. However, with time, patience and training, they can all be overcome. At present, there is no provision for any of these examinations in the General Ophthalmic Services contract.

The Local Optical Committee Support Unit (LOCSU) is currently developing a pathway for a specialist sight test (or enhanced service) for people with autism. The pathway is designed to provide information, support and improve access to eye care services thus ensuring that people with autism have good vision (with refractive correction supplied, as appropriate) and that any sight-threatening problems are detected and treated at an early stage. People with autism often require longer appointment times and several visits to the optical practice to become familiar with the environment and may need additional time with the optometrist so that the results of the eye examination can be explained.

Once the LOCSU pathway for People with Learning Disabilities (such as autism) is launched, we would be willing and delighted to work with NICE, the Department of Health and the NHS Commissioning Board to commend its early adoption to Clinical Commissioning Groups.

People with ASD, or any other disability for that matter, have an equal right to regular and comprehensive eye care as any other group (Disability Discrimination Act and the Equality Act 2010).

As recommended by the National Autistic Society, a person with autism should plan an informal trip

¹ D.R. Simmons et al. / Vision Research 49 (2009) 2705–2706

				<p>to their optical practice before the actual day of the examination. The involvement of the health professional at these times is extremely useful, in order that the person with an ASD can get to the optician, become accustomed to the room and any equipment, e.g. special chair, eye glasses. All of these components have been incorporated into the design of the aforementioned LOCSU pathway.</p> <p>More information is available here: http://www.autism.org.uk/working-with/health/patients-with-autism-spectrum-disorders-guidance-for-health-professionals.aspx</p>
2	NICE	general		<p>Studies have shown that the estimated prevalence of visual impairment or significant refractive error in people with learning disabilities is 52.43% in children, 62.3% in the 20-49 age group and 70.1% in the over 50s - significantly higher than for the population as a whole.²</p> <p>Most of this impairment is due to refractive error and can be corrected with spectacles; however people with learning disabilities are less likely to have sight tests and are also less likely to receive visual aids.³</p>
3	NICE	15	3	<p>Difficulties in diagnosis may be caused by undetected visual problems and hence, to avoid diagnostic overshadowing (i.e. where symptoms may be misinterpreted), an assessment of visual function should be considered and in many cases recommended before assuming particular symptoms or behaviours relate to autism.</p> <p>There is a need to have access to optometrists skilled in functional vision assessment and assessing patients with limited or no communication and poor cooperation. Care should be taken to rule out not only severe visual impairment, but also reduced visual acuity due to refractive error, cataract or other pathological causes. Optometric, orthoptic or ophthalmological input is required here too and we would be delighted to work with NICE on any related recommendations.</p>
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² The Estimated Prevalence of Visual Impairment among People with Learning Disabilities in England Eric Emerson & Janet Robertson – 2011 <http://www.improvinghealthandlives.org.uk/gsf.php5?f=10954>

³ McCulloch, D. L., Sludden, P. A., McKeown, K., et al (1996) Vision care requirements among intellectually disabled adults. Journal of Intellectual Disability Research, 40, 140–150
<http://onlinelibrary.wiley.com/doi/10.1046/j.1365-2788.1996.715715.x/abstract>

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

Closing date: 5pm on Friday 27 January 2012

PLEASE NOTE: The Institute reserves the right to summarise and edit comments received during consultations, or not to publish them at all, where in the reasonable opinion of the Institute, the comments are voluminous, publication would be unlawful or publication would be otherwise inappropriate.