

## **Draft revised statutory guidance to implement the strategy for adults with autism in England: consultation on new statutory guidance for local authorities and NHS organisations to support implementation of the Adult Autism Strategy for England**

The Optical Confederation represents the 12,000 optometrists, 6,000 dispensing opticians, 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.

The Local Optical Committee Support Unit (LOCSU) 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.

### **Consultation Questions:**

#### **1.1 Do you think that this guidance explains the responsibilities that local authorities and NHS bodies have around training for their staff and is sufficiently clear about what they should be doing?**

Yes, in that the guidance is clear that local authorities should by now be providing general autism awareness to all frontline staff in contact with adults with autism and that progress should be made with regard to specialist training for those with direct impact on access to services for adults with autism. However in our view more clarity is needed about the improvement mechanisms available if this progress is not occurring.

#### **1.2 Is the guidance on responsibilities reasonable?**

The guidance should include the role that optical professionals have with patients with autism. Optometrists and opticians predominantly work in community-based practices at primary care level, similarly to GPs. Further information on this is given in our response to Question 4.1.

**1.3 Do we need to highlight further the role that adults with autism and their families or carers should be playing in training programmes? If so, how?**

Yes, it is essential that adults with autism and their families or carers are engaged in autism awareness training. This should happen at an early stage of training programme development to ensure key messages are integrated into the foundations of the programme.

**1.4 What else do we need to include to ensure specific specialist autism training is provided to staff that carry out statutory assessments?**

All optometrists have undergone basic training in the care of people with learning disabilities or limited communications. Further detail on the role of optometrists and opticians, supplemented by the expertise of a multi-disciplinary team, is given in our response to Question 4.1.

**1.5 Would a description in the guidance setting out outcomes to be met at a particular level of autism training be helpful?**

No comment.

**1.6 Is there sufficient information on how health bodies should commission training?**

No comment.

**1.7 For local authorities and health bodies – is there anything in this section that you are not already doing or have not planned to do and therefore consider it unreasonable due to reasons of affordability?**

N/A

**1.8 Have you other comments on this section?**

No.

**2.1 Do you think this guidance explains the responsibilities that local authorities, NHS bodies have around assessment and diagnosis of autism for NHS and local authority staff and is sufficiently clear about what they should be doing?**

On page 17, reference is made to assessments of those identified as potentially having coexisting physical or mental health problems. We would like to see this either amended to say: 'physical, **sensory** or mental health problems' or mention made of sensory impairment in another way.

**2.2 If you are a commissioner of local care services, are you clear about what your responsibilities are? Are they reasonable?**

N/A

**2.3 If you are a CCG or other health body, are you clear about what your responsibilities are? Are they reasonable?**

N/A

**2.4 For local authorities and health bodies – is there anything in this section that you are not already doing or have not planned to do and therefore consider it unreasonable due to reasons of affordability?**

N/A

**2.5 Have you any other comments on this section?**

No.

**3.1 Do you think that this guidance appropriately summarises the responsibilities from the Children and Families Act that local authorities and their partners have around transition from child to adult services for young people with autism?**

No comment.

**3.2 In terms of young people with autism approaching transition without SEN statements or Education Health and Care Plan, is there anything further we should we be highlighting in the guidance to ensure they receive appropriate support?**

Due to the risk of diagnostic overshadowing at transition, young people should have an assessment of their visual function (sight test/eye examinations) as there is a higher prevalence of visual impairment in those with learning disabilities, as well as the teenage years being the time when myopia commonly develops. Behavioural changes due to poor vision may be misdiagnosed as due to autism spectrum disorder (ASD) or learning disabilities rather than being investigated and corrected. There is also a case for a report on visual function following people with ASD on transition from children's to adult services in order that appropriate provision is made.

**3.3 For local authorities and health bodies – is there anything in this section that you are not already doing or have not planned to do and therefore consider it unreasonable due to reasons of affordability?**

N/A

**3.4 Have you any other comments on this section?**

No.

**4.1 Are responsibilities for leading and joining up local partnership arrangements sufficiently clear?**

Although responsibilities for local partnership arrangements are addressed in this draft, it should be made clearer that CCGs have the ability to commission specialist pathways for people with learning disabilities including autism. We would like to draw attention to the LOCSU Community Eye Care for Adults & Young People with Learning Disabilities Pathway, delivered by local community based optometrists across the country.

This pathway has been developed by LOCSU's Clinical Advisory Group from established successful Learning Disability services provided by community optometrists in a number of areas, supplemented by the expertise of a multi-disciplinary team, and with advice and support from other leading eye health organisations and visual impairment charities through SeeAbility<sup>1</sup> and Mencap.<sup>2</sup>

People with learning disabilities are ten times more likely to have eye problems, but are less likely to receive timely and appropriate care, than the rest of the population.<sup>3</sup> The majority of people with mild learning disabilities should be able to have a sight test in any optical practice.

This pathway is designed to enable people with learning disabilities to access NHS sight tests in the same way as the wider population. It provides an enhanced sight test above the General Ophthalmic Services (GOS) contract sight test in a community setting, which gives optometrists more time to familiarise patients and their carers with the procedures and equipment at the time of the sight test and also gives time for repeat visits to complete procedures where needed. The pathway provides better preparation for patients and greater information sharing with the optometrist before the sight test via SeeAbility's 'Telling the optometrist about me' form, which helps make the experience a positive one and it also allows better feedback from optometrists to patients, regarding sight test results, using SeeAbility's 'Feedback from the Optometrist about my eye test' form.

It is essential that this pathway is available to as many people with learning disabilities, including autism, as possible. Given the number of CCGs across the country, and corresponding duplication of commissioning costs and effort, it is our professional view that national implementation of the above pathway would be the most efficient way of ensuring people with autism receive the eye health care they need and have a right to.

This could be achieved either as an additional service to the existing GOS contract, or by NHS England recommending the national pathway to CCGs for implementation. We would be very pleased to work with the Department of Health and NHS England to realise the objective of specialist eye health care for people with autism. Further information about this pathway is available on LOCSU's website:

---

<sup>1</sup> [www.seeability.org](http://www.seeability.org)

<sup>2</sup> [www.mencap.org.uk](http://www.mencap.org.uk)

<sup>3</sup> The Estimated Prevalence of Visual Impairment among People with Learning Disabilities in the UK Eric Emerson & Janet Robertson – 2011; Estimates of the number of adults in the UK with learning disabilities and visual impairment – summary report SeeAbility & RNIB – 2011; 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://www.locsu.co.uk/uploads/enhanced\\_pathways\\_2013/locsu\\_pwld\\_pathway\\_rev\\_nov\\_2013.pdf](http://www.locsu.co.uk/uploads/enhanced_pathways_2013/locsu_pwld_pathway_rev_nov_2013.pdf)

**4.2 If you have autism, or are a parent or carer of someone who has, is there anything further that organisations should do to ensure that your voice is heard in local planning?**

N/A

**4.3 Is any further advice or guidance needed on data collection and using data to plan effectively?**

Within LOCSU's Community Eye Care for Adults & Young People with Learning Disabilities Pathway, the collection of data on patient and carer experience including patient/carer reported outcomes is integral to the pathway design. Nationwide commissioning of this pathway by CCGs would provide commissioners with enhanced data and information on the local eye health needs of people with autism.

It is positive that from April 2014 this year local authorities must now record information about a person's primary reason for support and whether the person has reported certain other health conditions, including autism.

**4.4 For local authorities and health bodies – is there anything in this section that you are not already doing or have not planned to do and therefore consider it unreasonable due to reasons of affordability?**

N/A

**4.5 Have you any other comments on this section?**

No.

**5.1 Are the new duties on delivering preventative support at each tier of prevention under the Care Act sufficiently clear in relation to autism services, including how to promote wellbeing for a young person transitioning to adulthood?**

No comment.

**5.2 Do you agree with the description of preventative services provided?**

No comment.

**5.3 Is it clear how to develop preventative services according to local needs?**

No comment.

**5.4 For local authorities and health bodies – is there anything in this section that you are not already doing or have not planned to do and therefore consider it unreasonable due to reasons of affordability?**

No comment.

## **5.5 Have you any other comments on this section?**

No.

## **6.1 Is the approach to reasonable adjustments for people with autism sufficiently explained?**

One of the examples given in the draft consultation about planning and preparation is offering opportunities for adults with autism (and their family and carers if necessary) to visit 'an optician's prior to an eye test' (page 34). We fully concur with this.

LOCSU's Community Eye Care for Adults & Young People with Learning Disabilities Pathway includes provision for patient and supporting carers to visit the optical practice on one or more occasions before the appointment day to familiarise them with the surroundings, the personnel and with having a cover placed in front of each eye.

As described above, our view is that national availability of this pathway is essential to avoid health inequalities and engender excellent eye health care for people with autism and other learning disabilities.

## **6.2 Are the responsibilities of public services clear in regard to making reasonable adjustments to support people with autism?**

It is important that the statutory requirement of the need to make reasonable adjustments on public services does not negate the requirement for CCGs/NHS England to adequately fund extended appointment times, additional equipment and quiet spaces which may be necessary to provide appropriate services to people with autism. NHS organisations must ensure that the fees paid to providers are sufficient to allow them to afford to make 'reasonable adjustments' to service provision or pathways, and not inadvertently to create barriers to care through inadequate funding.

The Community Eye Care for Adults & Young People with Learning Disabilities Pathway has been specifically designed to meet the needs of this group. Nationwide commissioning of this national pathway would provide the funded time for optometrists and opticians to ensure that people with autism receive the eye health care they need.

## **6.3 For local authorities and health bodies – is there anything in this section that you are not already doing or have not planned to do and therefore consider it unreasonable due to reasons of affordability?**

N/A

## **6.4 Have you any other comments on this section?**

No.

**7.1 Do you think that this section of the guidance is sufficiently clearly worded and will be understood by health and social care professionals, commissioners, people with autism and parents/carers?**

The guidance helpfully makes clear that the provision of alternative community based settings for care for people with autism should be provided. This is also a key theme of NHS England's *Five Year Forward View*, which we support. Community based care reduces pressure on hospital eye services and offers enhanced convenience and well-being for patients. This is particularly the case for people with learning disabilities such as autism. Nationwide commissioning of the Community Eye Care for Adults & Young People with Learning Disabilities Pathway would provide an additional community service, information and support, where appropriate, to enable people with more complex learning disabilities to access NHS eye health services care (e.g. a sight test and any necessary visual correction) in a community setting like everyone else, while minimising stress and distress for people with learning disabilities when accessing eye care services.

**7.2 If not, what changes would you propose?**

We would like to see reference made to such specialist pathways included in the guidance.

**7.3 Does it cover all relevant requirements on the Mental Capacity Act, and the Mental Health Act?**

No comment.

**7.4 Is the guidance sufficiently clear about what NHS and local authority organisations and staff should be doing to improve services for people?**

We believe the guidance needs more clarity on the role of community services and specialist pathways.

**7.5 If you are a commissioner of local care services, are you clear about what your responsibilities are?**

N/A

**7.6 For local authorities and health bodies – is there anything in this section that you are not already doing or have not planned to do and therefore consider it unreasonable due to reasons of affordability?**

N/A

**7.7 Have you any other comments on this section?**

No.

**8.1 Do you think that this section of the guidance is clearly worded and will be understood by health and social care professionals, people with autism and parents/carers?**

No comment.

**8.2 If not what changes would you propose?**

No comment.

**8.3 Do you have any other comments on helping adults with autism into work?**

The only comment we would make is that national commissioning of the Community Eye Care for Adults & Young People with Learning Disabilities Pathway will ensure that people with autism receive the eye health care they need in a comfortable environment, and given the importance of eye health to individual health and well being, this would play a role in helping adults with autism into work.

**8.4 How should local authorities ensure that social care support and planning for people with autism is working effectively with employment support, including Job centres?**

No comment.

**8.5 For local authorities and health bodies – is there anything in this section that you are not already doing or have not planned to do and therefore consider it unreasonable due to reasons of affordability?**

No comment.

**8.6 Have you any other comments on this section?**

No.

**9.1 What more could be included on how local authorities and the NHS should work with criminal justice system partners?**

No comment.

**9.2 Is the process for Liaison and Diversion sufficiently explained?**

No comment.

**9.3 Do you have any other comments on helping to support people with autism who come into contact with the criminal justice system?**

No comment.

**9.4 For local authorities and health bodies – is there anything in this section that you are not already doing or have not planned to do and therefore consider it unreasonable due to reasons of affordability?**

N/A

**9.5 Have you any other comments on this section?**

No.

**December 2014**