# Good practice guidelines for Eye Clinic Liaison Officers (ECLOs)

## People with learning disabilities

This guide is one of a set of guidelines available for Eye Clinic Liaison Officers (ECLOs).

### Purpose

This good practice guideline is to inform ECLOs about considerations and appropriate support for people with Learning Disabilities, within eye clinics.

There are estimated to be more than one million adults in the United Kingdom with a learning disability. A learning disability is a lifelong condition that means people may need support to:

* understand new information.
* learn new skills.
* cope independently.

It is important to remember that everyone with a learning disability is an individual. Different people will have different areas of life that they need support with.

### Key health messages

* People with learning disabilities are 10 times more likely to have serious sight problems than other people [1].
* People with learning disabilities may not be able to tell you about their sight loss. Many people who know the individual think they can see perfectly well.
* People with learning disabilities who require glasses may need support to get used to them. Six in 10 people with learning disabilities need glasses and often need support to get used to them.
* Follow up appointments are important; people may need additional support to attend these.

### Sight loss and learning disabilities

* It should be recognised that many people with learning disabilities experience age related eye conditions significantly earlier than the general population.
* In addition, people with learning disabilities may have difficulties with processing visual information, which can exacerbate existing or newly diagnosed eye conditions.
* People with learning disabilities may not meet certification criteria if their visual difficulties are solely related to visual processing problems, rather than an identified eye condition.

### Practice considerations

It is a statutory requirement under the Equality Act (2010) and the NHS and Social Care Act (2008) that public sector agencies make "reasonable adjustments" to their practice that will make them as accessible and effective as they would be for people without disabilities.

* Multiple appointments may be required to gain trust and confidence in the staff within the clinic to enable a full examination, reduce anxiety and work towards positive outcomes.
* It may be most appropriate for the individual to attend the clinic when it is at its quietest. This could be one of the first appointments of the day or one of the last appointments. Allow extra time for these appointments.
* Referrals and additional support or information may be required when making onward referrals to rehabilitation or low vision services.
* Ensure that all information is sent to the individual and carers in appropriate formats, and where consent is given, that other relevant care organisations are included.

### What can make a difference?

#### Communication:

* Always include the individual and their carer(s) in discussions. Ask the person and carer what reasonable adjustments would help them for the appointment.
* Refer to the Communication Passport if available and ensure that communication guidelines are followed during the clinical appointment. **A Communication Passport** provides a practical and person-centred approach to passing on key information about people with complex communication difficulties who cannot easily speak for themselves. Please see Appendix 1 ([link to Appendix 1](#_Appendix_1)) for more information.
* Allow the individual time to understand and respond.
* Use simple language and short sentences, one idea or question at a time. Sensitively check understanding by asking open questions.
* It may be necessary to repeat information, or repeat the information slightly differently, if the person is unsure.
* Take your time to explain information. People with learning disabilities may take longer to understand the information provided.
* Provide written information in an easy read format to help understanding.

#### Recommendations:

* When making referrals for the potential use of aids or adaptations, discuss these referrals with the individual, their family members and carers, to ensure that the referral is appropriate, of benefit to the person, and that it could improve their quality of life.
* If new glasses are prescribed, suggest that they are labelled or marked appropriately, such as for reading or distance.
* The impact and severity of the person’s sight loss may not have been previously fully appreciated, as their sight loss may have been masked and behaviours attributed to the person's learning disability.
* The ECLO should also support family members and carers to understand the eye condition and sight loss.
* Promote the inclusion of vision information into care plans and health action plans.
* The ECLO should promote the inclusion of relevant information from the Ophthalmologist within the Communication Passport. This could include highlighting working distances, the best side to approach, appropriate font and pictorial size. Changes to the Communication Passport would be made by the family member or support worker.
* Consideration must be given to ocular medications e.g. administration, labelling, usage, their impact and compliance.

#### Legal considerations – consent and capacity:

* If the ECLO is unsure if the person has capacity to consent, this should be discussed with family members, support staff or General Practitioners who will advise.
* Adults are considered to have capacity to consent, including those with learning disabilities, unless legally determined otherwise.
* Only an individual who has undergone appropriate incapacity training can decide if an individual has or has not got capacity to make an informed decision.
* Capacity to consent in the first instance is assessed by health care professionals, such as a General Practitioner, Psychologist or Consultant. The Mental Capacity Act (2005) (England, Wales and NI) and the Adults with Incapacity (Scotland) Act (2000) are the relevant legislative documents relating to this ([Appendix 2](#_Appendix_2) has links to these documents).

### Signposting and useful resources

#### RNIB Older People and Complex Needs team

Access to resources specifically to support people with learning disabilities. These include tip cards on:

* Communication
* Mobility
* Environmental recommendations
* Supporting someone with learning disabilities to wear their glasses.

Link to webpage: <https://www.rnib.org.uk/professionals-social-care-professionals-complex-needs-social-care/learning-disabilities>

#### SeeAbility

<https://www.seeability.org/>

**SeeAbility is a specialist registered charity enriching the lives of people who have sight loss and other disabilities. It provides easy to read eye care information to support accessing the optometrist and understanding eye conditions.**

#### Royal College of Ophthalmology

<https://www.rcophth.ac.uk/?s=learning+disabilities>

The Royal College of Ophthalmology champion excellence in the practice of ophthalmology through standards in training, education and assessment of ophthalmologists; supporting the promotion of research and innovation throughout the ophthalmic community.

#### Mencap

<https://www.mencap.org.uk/>

Mencap is a leading voice in the field of learning disability, focused on valuing and supporting people with a learning disability, and their families and carers.

#### Information about Easy Read information

[About Easy Read - Easy-Read-Online Limited](https://www.easy-read-online.co.uk/about-easy-read/)

##### Photosymbols

<https://www.photosymbols.com/pages/easy-read>

Photosymbols are a form of easy read information designed for people with a learning disability who like clearly written words with pictures to help aid understanding.

### Support

Specialist services within RNIB:

* RNIB Older People and Complex Needs team provide training and consultancy services to carers, professionals and organisations. For more information, contact us at [olderpeopleandcomplexneeds@rnib.org.uk](mailto:olderpeopleandcomplexneeds@rnib.org.uk) or on 0141 739 3682.
* RNIB Visual Impairment, Learning Disabilities and Complex Needs services, based in Glasgow and Fife provide building based and community services. For further information please visit: <https://www.rnib.org.uk/scotland-how-we-can-help-learning-disability-outreach-and-assessment-scotland/day-support-and>

This Good Practice Guide was written by:

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* RNIB Evidence and Service Impact team

The original guide was peer reviewed by a panel of ECLOs and their managers from across the sight loss sector. Updates were supported by RNIB Older People and Complex Needs team and reviewed by Eye Care Support Services.

## References

[1] Emerson, E., & Robertson, J. (2011). "Estimated prevalence of visual impairment among people with learning disabilities in the UK". London: Royal National Institute for the Blind & Seeability Learning Disabilities Observatory. Available from:

<https://www.rnib.org.uk/knowledge-and-research-hub/research-reports/prevention-sight-loss/prevalence-VI-learning-disabilities> (Accessed 23/11/20).

## Appendix 1

A Communication Passport provides a practical and person-centred approach to passing on key information about people with complex communication difficulties who cannot easily speak for themselves.

A Communication Passport does this by:

* Describing the person’s most effective means of communication, so that others can be better communication partners.
* Drawing together information from past and present, from many people who know the person, and from different contexts.
* Presenting the person positively as an individual, not as a set of "problems" or disabilities.

A communication passport is a way of supporting a vulnerable person with communication difficulties across transitions, drawing together complex information (including the person’s own views, as much as possible) and distilling it into a clear, positive and accessible format. This helps staff and conversation partners to get to know the person with communication disabilities. They can then interact and respond consistently to help the person make sense of events and get the best out of what communication abilities they do have.

A communication passport is a vital tool in "joined-up" inter-agency planning and working. It promotes partnership with families and is an excellent a way of implementing and recording consultation and participation of the individual.

The communication passport belongs to the person, not to staff or family, though they may help him or her to use it appropriately and update it. Passports are especially important at times of transition, when new people come into the person’s life and information may not be passed on. They are also helpful when new or temporary staff or volunteers meet the person, helping them to quickly acquire key information, or for example, introducing a person to a new foster family.

The process of creating a passport can help with assessing people and their needs, and in identifying gaps in assessment. For more information visit:

<http://www.communicationmatters.org.uk/page/communication-passports>

## Appendix 2

Mental Capacity Act 2005 (England, Wales, Northern Ireland)

<http://www.legislation.gov.uk/ukpga/2005/9/contents>

Adults with Incapacity Act 2000 (Scotland)

<http://www.legislation.gov.uk/asp/2000/4/contents>

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Document ends.