



THE MANAGEMENT OF VISUAL PROBLEMS IN ADULT PATIENTS WHO HAVE LEARNING DISABILITIES

Introduction

Vision is the key to learning, communication and movement. The more people can see, the easier it is for them to understand and control their environment. Ophthalmologists are therefore in a unique position to help people with learning disabilities – including people born with visual impairment and people with acquired sight loss. There are many anecdotal reports of intervention by ophthalmologists substantially improving the quality of life of adults with learning disabilities (LD). Alleviating visual impairment may allow significant improvements in a person's ability to self-care with resultant economic benefits through reduced need for supervision and support. The improved independence experienced should result in both an enhanced quality of life and greater self-esteem for the person concerned.

There are estimated to be over one million people in the UK with a learning disability. People with learning disabilities may not know they have a sight problem and may not be able to tell people. Many people think the person with learning disability they know can see perfectly well. Adults with learning disabilities are 10 times more likely to be blind or partially sighted than the general population. An estimated 96,500 adults with learning disabilities (including 42,000 known to the statutory services) are blind or partially sighted. 6 in 10 people with learning disabilities need glasses and often need support to get used to them. People with learning disabilities need to have a sight test every two years, sometimes more often¹.

The range of abilities among people with learning disabilities and the scope of ophthalmic disease are vast.

The aim of this document is to provide ophthalmologists with guidance and support so as to enable them to provide insightful and quality treatment to patients with LD. This document may also challenge the attitude that providing effective services for people with learning disability is unachievable.

It will advise on how reasonable adjustments and the use of simple resources, already freely available, can enable all ophthalmologists to improve quality of care and outcomes in people with learning disability (PWLD).

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The challenge

There is a perception that in the 'target driven' NHS, the additional resources (time, money) required to effectively manage PWLD is difficult to find. We need to challenge these perceptions and show that the legally required adjustments are within reach.

Key areas for improvement include:

1. **Definition and impact of vision problems in learning disability** (page 3)
 2. **Recognition of eye disease in people with learning disability** – common signs, symptoms, associations and the role of screening and annual GP Health Checks (page 8)
 3. **Team work and planning care** - working closely with the person with Learning Disability and his/her family, carers and/or supporters to gain that person's trust and co-operation both in clinic and at surgery (page 10)
 4. **Communication** – most doctors lack specific training in communicating with people with learning disability. Effective communication between health and social care is particularly important (page 12)
 5. **Accessible information** - helping family carers and supporters to prepare people appropriately and reduce anxiety (page 13)
 6. **Consent** – working in partnership with patients and carers to enable consent or involving best interest meetings and independent advocacy where necessary (Page 14)
 7. **'DNA' Policies and Vulnerable Patients** –special consideration needs to be given to the follow up of those who miss appointments (page 16)
 8. **Promoting equality of access to services** – legal obligations and reasonable adjustments (page 17)
 9. **Supporting people with learning disability and low vision** (page 21)
 10. **Promoting effective provision of services** – commissioning care and models for effective delivery of ophthalmic care for people with learning disability (Page 23)
- Conclusion:** What every ophthalmologist can do (page 25)



1. Definition and impact of vision problems in learning disability

What do we mean by “learning disability”?

The term ‘learning disability’ is used throughout this document to ensure distinction from the broad range of learning difficulties that may impede educational attainment in people within the average range of intelligence. Valuing People defines learning disability as the presence of²

- A significantly reduced ability to understand new or complex information, to learn new skills
- A reduced ability to cope independently (impaired social functioning)
- Occurring before adulthood, with a lasting effect on development

This means that people with learning disability will have difficulties in understanding, difficulties in learning new things and generalising these to new situations, and difficulties with social interaction; each of these vary dependent upon the extent and nature of the disability.

LD includes patients with and without an additional medical cause for learning disability; those who were educated within mainstream schools or schools for children with special needs; those with a static or progressive condition.

There are estimated to be over one million people in the UK with a learning disability. People with learning disabilities may not know they have a sight problem and may not be able to tell people. Many people think the person with learning disability they know can see perfectly well. Adults with learning disabilities are 10 times more likely to be blind or partially sighted than the general population. An estimated 96,500 adults with learning disabilities (including 42,000 known to the statutory services) are blind or partially sighted. 6 in 10 people with learning disabilities need glasses and often need support to get used to them. People with learning disabilities need to have a sight test every two years, sometimes more often¹.



Table 1

Major causes of learning disability in United Kingdom³

- Prematurity
- Chromosomal disorders
 - Down's syndrome
 - Fragile-X syndrome
- Cerebral palsy
- Genetic Disorders
- Metabolic disorders
- Toxins (alcohol, drugs, iatrogenic)

An increase in the prevalence rates for adults with learning disabilities in England is anticipated over the next two decades for three reasons⁴

1. The increase in proportion of younger English adults who belong to South Asian minority ethnic communities;
2. Increased survival rates among young people with severe and complex disabilities;
3. Reduced mortality among older adults with learning disabilities

The life expectancy of people with learning disabilities is increasing over time (currently 67 years for men, 69 for women and 55 for people with Down's syndrome). Ophthalmology clinics will increasingly encounter patients with learning disability presenting with age related conditions such as cataract and glaucoma.

Progress

Since the publication of the white paper, 'Better services for the mentally handicapped' in 1971, there has been considerable progress in closing large institutions and developing services in the community².

The majority of people with learning disabilities live with a parent or other relative. However, people with more severe learning disabilities are more likely to be living in residential care homes and NHS accommodation than people with less severe disabilities⁸.

Many people with learning disabilities have additional disabilities such as epilepsy, visual impairment, hearing deficit and mental health problems.



Table 2

Causes of Visual Impairment in People with Learning Disability³

- refractive error
- amblyopia
- strabismus
- congenital cataract
- nystagmus
- corneal problems
- optic pathway abnormalities
- perceptive and interpretive problems

Visual impairment in learning disability

Adults with learning disabilities are 10 times more likely to be blind or partially sighted than the general population. An estimated 96,500 adults with learning disabilities (including 42,000 known to the statutory services) are blind or partially sighted. The estimated prevalence of blindness and partial sight in the adult learning disabilities population is 9.3%. This means that nearly one in ten adults with learning disabilities is blind or partially sighted¹.

Thousands of people with learning disabilities have unidentified sight problems. Visual impairment compounds the other disabilities that people with learning disabilities already have.

Sight problems may affect people with learning disabilities in many ways:

Social inclusion and isolation – Sight helps people take part in the world around them. It helps them understand if they are included in what is going on, or excluded. People with sight loss and learning disability are at risk of social isolation and exclusion from ordinary community facilities.

Motivation - Poor sight may reduce people's motivation to discover and control their world. Visually impaired children and adults with learning disabilities often seem to be lacking in 'drive'. People who have not learned that they have the power to control their environment may appear compliant or passive.

Communication and behaviour – Visual impairment makes communication with others more difficult particularly communication through facial expression.



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Visual impairment may affect:

- The ability to make eye contact
- Taking turns to talk
- Understanding facial expression, body language and gestures
- Learning and using sign language
- Understanding what behaviour is thought by society as a whole to acceptable and what is not.

Co-ordinating other senses – Sight helps people understand what they have heard, touched or tasted. Sight allows people to predict, anticipate and make choices. It also helps people to use their eyes to direct their hands and feet. People with sight loss and learning disabilities need longer to explore and complete tasks. People will find it difficult to anticipate and predict the actions of others and have significant difficulty in learning new tasks.

Monocular vision in learning disability

In the general population loss of sight in one eye can have profound and long-term effects. People with learning disabilities are more likely to have difficulties in adapting to the changes in their vision and the way they perceive their world. Coping strategies that non-learning disabled people learn through trial and error may well need to be taught to people with learning disabilities. Some people may have a lack of understanding of what has happened to their sight.

People will need support in coping with the distress at the loss of sight.

http://www.lookupinfo.org/eye_care/eye_care_factsheets/about_monocular_vision.aspx



Paediatric learning difficulty

Impaired vision in childhood impacts upon all other areas of development, particularly motor development and speech. In children with coexisting learning difficulty, the effect may be compounded.

The majority of children with severe visual impairment and blindness have additional non-ophthalmic disorders or impairments. 48% of severe visual impairment and blindness in the UK is associated with disorders of the cerebral visual pathways⁵ Co-existing impaired visual development, ocular disease and learning difficulties are commonly associated with the following conditions:

- Down's syndrome (see table 3)
- cerebral palsy
- prematurity
- severe learning disability
- congenital infection
- hydrocephalus
- neurodegenerative diseases
- deafness
- inherited eye diseases
- cranio-facial disorders

Table 3

Ophthalmic pathology associated with Down's Syndrome

- Refractive errors including hypoaccomodation
- Strabismus
- Nystagmus
- Cataract
- Glaucoma
- Kertoconus

Routine vision and orthoptic screening for these high-risk groups occurs in several regions to facilitate early intervention where necessary.



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Some children may have difficulty processing images and parents report poor functional vision despite normal acuity and examination. Various strategies have been described to help these children use their vision to reach their full potential⁵. Early referral to the visual impairment team is important for all children with a visual impairment, regardless of CVI registration, to provide support for the child and carers within the education sector.

Not all healthcare regions fund school screening (vision testing at age 4-5 years) outside mainstream schools so children with a learning disability are less likely to be able to benefit. Ophthalmologists are encouraged to highlight areas of inequality with those involved in commissioning

2. Recognition of eye disease in people with learning disability

Signs and symptoms

Sight loss may be gradual and go unnoticed by family or carers. The assumption may be made that the deterioration in behaviour is part of the person's general learning disability condition or attributed to depression, aging, dementia or even abuse.

A change in visual function may not be easily communicated by someone with a learning disability. It may manifest itself as a change in behaviour or withdrawal. Unless staff have experience in dealing with patients with learning disabilities, these symptoms may not be recognised. Frequent changes of staff caring for people with learning disabilities may also lead to failure to recognise a change in behaviour that has resulted from loss of vision.

Because of difficulties expressing themselves, some people with learning disability may exhibit adverse behavioural changes as a result of impaired vision. Even a small deterioration in vision may cause distress.

Ophthalmologists should be aware that a change in behaviour may signify visual loss.



Table 4

Signs and Symptoms of visual loss in people with learning disability

Examples of behaviour associated with sight loss in people with learning disability:

- Anxiety in unfamiliar situations
- Unwillingness to venture out of their immediate environment or be involved
- Hesitancy on steps, at pavement edges or in poorly lit areas
- Depression
- Anger or frustration
- Eye poking or rubbing
- Reduction in social or domestic skills and participation
- Loss of interest in family, friends, TV or social activities
- Undue alarm at unfamiliar noises or when approached

Eye rubbing or eye touching⁶

Eye-poking in people born with visual impairment has long been documented. It provides visual rewards to people whose lives may be lacking in colour and interest known as 'phosphene entopic phenomena'.

As sighted and visually impaired people with learning disabilities may poke, rub or touch their eyes for many reasons, it is important to obtain help from a psychologist (contacted via the local a Community Learning Disability Team) if this behaviour presents problems for surgery.

Persistent or intense periods of eye-poking, head-banging and other forms of self-injury to the head pose special difficulties for family carers and staff trying to examine and decide upon treatment. Supporters may worry that people may touch or rub their eyes after an operation. Eye poking may decrease following cataract surgery with the associated improvement in vision.



Table 5

Causes of eye rubbing or poking in people with learning disability:

- Self-stimulation and entertainment
- Communication or attracting social attention
- Reduction in vision
- Keratoconus
- Allergies and/or hay-fever (seasonal)
- Eye infections, eyelash, eyelid and skin problems
- Dry eyes
- Glasses - poor fitting or incorrect refractive power
- Tiredness
- Stitches not being removed after eye surgery
- Self-injury

Further information can be found at

http://www.lookupinfo.org/eye_care/eye_care_factsheets/eye_poking_and_touching_in_people_with_learning_disabilities_an_introduction.aspx

3. Team work and planning

The key to success is identification of people with learning disability in primary care settings

This is one of the biggest challenges facing the health and social care network in improving care. Most of the adjustments which can be made simply and at low cost require health care providers to know the patient has additional needs prior to attending clinic.

Patients with LD are not well “flagged” on current healthcare IT systems. This means the clinician may not be prepared for them and have the resources (time, space, facilities, support) available in clinic. **Ophthalmologists should be proactive in identifying people with learning disability** who attend clinic in order to ensure they receive an appropriate level of care. This is most effective if done when triaging referrals so adequate preparation can be offered to the patient and their carer, which will in turn make the hospital visit go more smoothly and efficiently.

Planning the visit to Eye Clinic

People with learning disability may be wary of new situations. Many patients benefit from attending with a known and trusted carer. Some may require a visit to the clinic to familiarise them with the layout and equipment. **Ophthalmologists should be**

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aware that people with learning disability may have a written health record that sets out how they prefer to be treated – this may be called a ‘patient or health passport’, ‘hospital book’, or ‘traffic lights system’.

These documents are a simple tool to inform acute staff about important aspects of a person's life, to help them to 'get it right first time'). The document can be completed with the person/carers in their own home; by learning disability services staff before admission to hospital; within primary care; at pre-assessment; or in the acute hospital on admission.

They seek to reduce an individual's vulnerability by making a connection between the people who know them best, such as parents, carers, community nurses or key workers, with those who know them least - acute staff. Passports provide key information such as known medical conditions and details of any medications taken, which can help acute staff to understand patients' needs and therefore develop appropriate care plans.

Easy Read leaflets are available to help the patient prepare for an eye test so they might be better able to anticipate what will happen⁷. Some people with learning disability will require more than one visit to gain trust and confidence with the doctor to allow a full examination. **Ophthalmologists should work closely with carers to accommodate each patient's individual requirements** (e.g. additional visit, quiet waiting area, minimal waiting time). These are examples of the reasonable adjustment required as part of the Equality Act⁸. Some people with learning disabilities need basic preparation before the appointment – such as visiting the clinic, meeting the staff, practicing putting their chin on the slit lamp etc.

The success of treatment, especially surgery, for people with learning disabilities is often totally dependent on having a clearly identified and recorded plan of support that has been prepared before the actual admission and treatment.

Clinicians need to ensure that family carers and/or staff working with people with learning disabilities can provide an appropriate level of support to individuals before, during and after treatment. A staff support package (covering both pre-operative and post-operative care) is crucial. This plan should identify preparation work that needs to start before admission – such as getting individuals used to having eye drops inserted or wearing a patch. Familiarisation may take weeks or even months.

People with learning disabilities often rely on their families to support them in relation to their health. Family of people with complex health needs often have great expertise about their relatives' conditions, treatment and important considerations. Failure to respect this expertise can pose serious clinical risks.

Learning Disability Link Nurses/Acute Link Nurses - An increasing number of learning disability link nurses are now employed in general hospitals. Their role is to

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facilitate treatment by advising health professionals how to work with people with learning disabilities.

Involvement of a Learning Disability Liaison Nurse early in the planning of surgery has been shown to yield benefits to all members of the team as well as the patient. Where familiarisation programmes have proved unsuccessful, it is important to consider alternative approaches – such as

- Modification of post operative topical treatment regime
 - Use of intracameral antibiotic
 - Use of subtenons or orbital floor steroid
- The person wearing sun-glasses during the daytime to remind them not to touch their eyes.

4. Communicating with patients

Clinicians are not trained specifically in alternative ways of communication. Medical training pays inadequate attention to equipping staff with skills to assess and deal with the varying individual needs of people with learning disability².

People with LD may need extra time to understand or think about options presented to them. They may need support from a carer. Literature is available through LookUp in “Easy Read” format which uses plain language and illustrations to explain parts of the eye examination⁷¹. These should be used where appropriate, rather than providing the carer or patient with the standard clinic leaflet. Advice regarding using eye drops or helping a patient learn to accept spectacles is available.

People with learning disabilities may have had negative experiences of medical appointments and be wary of professionals who invade their “personal space”. It is beyond the scope of this document to explain in detail how ophthalmologists should communicate with people with learning disabilities, but people with learning disabilities and guidance have stressed the following:



Table 6

Ophthalmologists should be aware of the following guidance on communication with people with learning disability.

- Talk to person, not their supporter or carer.
- Speak slowly and clearly.
- Explain procedures in easy words.
- Explain and/or demonstrate the equipment to be used.
- Do not touch people without warning – give them time to show they have consented to being examined.
- Do not hurry people – they may get upset and less willing to co-operate.
- Ask if the person has a written health record that sets out how they prefer to be treated – this may be called a ‘patient or health passport’, ‘hospital book’, ‘traffic lights system’ etc

5 Accessible information

Information with easy words and pictures for patients with learning disabilities is available. Having Easy Read information helps supporters to prepare people appropriately and reduce anxiety. Ophthalmologists may consider individual letters to patients with learning disabilities explaining the treatment process allowing them time to reflect and discuss care with friends and family.

LookUp have produced feedback forms for health professionals and carers to complete. These forms include pre and post eye clinic forms, pre and post optometry forms and an eye surgery support plan and explain in appropriate language the outcome of the appointment. They are an essential part of the process to ensure both patient and carer understand what treatment is needed and why, even if this is simply wearing glasses to watch TV or when reading. They can be used instead of a dictated clinic letter and copied to the GP. **Feedback forms are particularly helpful when the person is cared for by staff in different settings.** This aids compliance with treatment and enhances links across the social and health care network.

Eye clinic staff should also be encouraged to complete the appropriate pages of the patient held recode (Passport or Personal Health Profile).



6. Consent

A full review of the Mental Capacity Act is available in the ophthalmic services folder. **Ophthalmologists should ensure that where possible, people with learning disability are enabled to consent for themselves:** this not only applies to surgery, but to routine clinic procedures such as dilating drops and slit lamp examination. Appropriate literature, additional time, support from a carer or the services of an IMCA (independent mental capacity advocate) may need to be sought. Where there is doubt, a best interests meeting should be arranged. **Concerns around consent should not preclude people with learning disability from benefiting from surgical intervention.**

In all patients, case-by-case assessment to determine whether the person has the capacity to make the decision in question should be performed. Each intervention should be viewed separately. Each person's ability to consent can change over time so consent needs to be considered in every instance. Readers are directed to LookUp, which contains numerous examples of misconceptions surrounding people with learning disability and surgery and suggestions for adapting protocols to allow people with learning disability⁶. With adequate preparation and desensitisation successful and safe surgery is achieved in many patients.

Mental Capacity Act 2005

This applies in the formalities around consent for operative procedures, but is also relevant in the clinic where decisions have to be made on routine part of examination such as the use of dilating drops.

Ophthalmologists should be familiar with

- The Royal College of Ophthalmologist Guidelines for Cataract Surgery which contains information on consent and assessing capacity⁹
- GMC guidance on the Mental Capacity Act¹⁰ (Consent guidance: patients and doctors making decisions together)

The Mental Capacity Act lists five principles to consider when deciding if a patient is capable of making decisions.

1. Presumption – every adult has a right to make a decision and should be assumed to have capacity until proved otherwise
2. Right to be supported in decision making – be provided with all appropriate help before concluding they cannot make a decision – this includes accessible information about the treatment and the possible involvement of an independent mental capacity advocate.
3. Right to make an eccentric decision – often we don't consider competence if a patient makes the decision we feel is right: competency is only questioned if



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they make what we consider to be the “wrong” decision. A competent patient’s right to make an informed eccentric decision should be respected.

4. Best interests – we should always make the decision which is in the patients best interests and for no other reason – e.g. whether we are concerned about the possible need to hold or restrain the patient after surgery
5. Least restrictive option – could the same objective be achieved in another manner: that is less restrictive of the person’s rights and freedom.

If patients are not able to make decisions for themselves, the doctor must work with those close to the patient and with other members of the healthcare team. The doctor must take into account any views or preferences expressed by the patient and must follow the law on decision-making when a patient lacks capacity.

Family carers and staff can support the process of gaining the person’s consent. They can also contribute as part of the multi-disciplinary team when the person’s best interests are discussed.

Consent and the role of independent mental capacity advocates

If there is uncertainty around determining best interests, an IMCA (Independent Mental Capacity Advocate), the person’s advocate, and the local Community Learning Disability Team and key supporters’ opinions should be sought.

The duties of an IMCA are to:

- support the person who lacks capacity and represent their views and interests to the decision-maker
- obtain and evaluate information, both through interviewing the person and through examining relevant records and documents
- obtain the views of professionals providing treatment for the person who lacks capacity
- identify alternative courses of action
- obtain a further medical opinion, if required, and
- prepare a report (that the decision-maker must consider).

IMCAs are not decision-makers for the person who lacks capacity. They are there to support and represent that person and to ensure that decision-making for people who lack capacity is done appropriately and in accordance with the Mental Capacity Act. More information is given at www.dh.gov.uk/imca and in chapter 10 of the Mental Capacity Act (2005) Code of Practice.



7. 'DNA' Policies and Vulnerable Patients

People with learning disability are “vulnerable patients” and should be exempt from Trust DNA policies. While they remain unflagged on systems this poses a challenge.

Ophthalmologists should resist departmental protocols which routinely discharge patients who do not attend.

It is important identify from referrals if a patient may be a vulnerable patient and consider offering another appointment. There may be instances where person with learning disability requires support to attend and this has not been made available so the patient is not brought to clinic. This is a potential source of discrimination and attempts should be made ensure the patient's attendance is enabled.

In paediatric practice, recurrent DNA behaviour might (possibly, should) raise concerns about the child's welfare, and trigger a Social Services assessment. A similar approach may have merit in patients known to have learning disability, or other cognitive problems.

Where a patient is known to have LD and visual impairment, alternative methods of communication with the patient other than postal letter should be considered.

Although the problem of poor reading vision is neither universal nor exclusive to patients attending Eye clinics, many patients would be anticipated to have significant sight problems which must be taken into account in Hospital communications.

Considering Restrictive Physical Intervention (RPI)

The vast majority of people who require surgery proceed without the thought of any physical intervention but a reality for some is that carers have this concern whenever faced with the possibility of a person having to receive sight saving or even life saving treatment.

Careful discussion and planning is required when there is any question that a person with learning disabilities might possibly need some form of 'restraint' or physical intervention. Concerns over the use of RPI should be raised at best interests meeting. Services need to actively work to avoid physical intervention whenever possible and care needs to consider strategies which can support best interests as well as meeting the needs of each individual in a respectful manner. Advice should be sought from psychologists based in local Community Learning Disability Teams.

The British Institute of Learning Disabilities provides basic guidance on physical interventions. http://www.bild.org.uk/03behaviour_pi_pp.htm



8. Promoting equality of access to services

People with learning disabilities have the same rights of access to NHS ophthalmic care services as any other people. There are however reports of adults having their congenital visual impairment identified in their 50s and 60s. Many adults with learning disabilities have never had eye tests. Patients with learning disabilities are less likely to know how to access services in order to improve their visual function. They may not know about eligibility for free eye tests and worry about the cost of glasses. Family carers and supporters may be unaware of the incidence of visual impairment and the importance of regular examinations. Whilst there is an increase in people with learning disabilities having regular eye tests, only 52% had their eyes tested in the last year¹¹.

Unidentified eye problems may cause pain, lower potential and undermine successful participation in a range of activities. Simply correcting refractive error or presbyopia can enhance quality of life for many people with learning disability.

Improving & adapting services

Many recent reports demonstrate that people with learning disabilities have higher levels of unmet need and receive less effective treatment. Healthcare for All¹² - the Independent inquiry into access to healthcare for people with learning disabilities - reported that:

- There is insufficient attention to making reasonable adjustments to support the delivery of equal treatment. Adjustments are not always made to allow for communication problems, difficulty in understanding or the anxieties and preferences of individuals concerning their treatment.
- Parents and carers of adults and children with learning disabilities often find their opinions and assessments ignored by healthcare professionals, even though they often have the best information about, and understanding of, the people they support.

There is clear intention on the part of the government to ensure that patients with learning disabilities are not disadvantaged in access to healthcare, but there is still a need to reduce the gap between policy and practice.

People with learning disability are less likely to receive appropriate investigation, screening and treatment than those in the general population. There are significant barriers to accessing treatment. The treatment received is less likely to be evidence based¹².



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There are currently 3 pieces of legislation which place obligations upon commissioners and providers to ensure people with learning disability have the same rights of access to NHS ophthalmic services as everyone else.

Ophthalmologists are encouraged to act as advocates for people with learning disability, highlight areas of inequality and work with commissioners to enable access to services.

Equality Act 2010⁸

The Equality Act “harmonises and extends” simplifies the multiplicity of legislation which has governed discrimination and aims to make the law consistent, clearer and easier to follow in order to make society fairer.

Within the Equality Act, disability is defined as a person who has a physical or mental impairment that has a substantial and long-term adverse effect on their ability to carry out day-to-day activities.

The act applies to everyone who provides a service to the public or section of the public, those who sell goods or provide facilities. It applies whether or not a charge is made. It prohibits direct discrimination, indirect discrimination and enables positive action.

Examples of inequality in providing ophthalmic care for people with learning disability would include, but are not limited to, access to diabetic retinopathy screening, glaucoma screening, sight tests, exclusion from surgery because of technical problems (biometry, consent, uncertainty over benefit).

Direct discrimination

This occurs when someone is treated less favourably than another person because of a protected characteristic. This now extends to include people with a disability, people linked with disability (for example sibling or carer) or those wrongly assumed to have a disability.

Example: Someone with learning disability may have a carer to assist them only during fixed hours/days. Discrimination would arise if there was persistent failure to provide appointments at a time when the patient’s advocate or carer is able to attend with the patient to support them.

Example: Failure to provide school vision screening to children attending specialist schools.



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Indirect discrimination

Indirect discrimination applies where a policy or practice is applied in the same way to everyone, but in doing this places disabled people at a disadvantage. Exceptions may be granted if they can be justified and show that the rule policy or practice is intended to meet a legitimate objective in a fair balanced and reasonable way. Lack of financial resources is unlikely to be considered a sufficient justification.

Example: Requiring patients to respond to a “choose and book” letter in order to arrange an out patient appointment.

Example: Criteria used to prioritise cataract surgery based on driving, reading and working. Consideration of independent living, reduced disorientation and requirement of lip reading or makaton sign language for communication are more often important considerations in people with learning disability.

Example: A stand-alone clause requires public bodies to provide accessible information. LookUp and Mencap provide Easy Read leaflets which will help people with learning disability understand and prepare for eye clinic¹.

Positive Action

This is a process where people who are at a disadvantage linked to a characteristic receive additional resources or help. The positive action provision enable public sector organisations to take proportionate steps to help people overcome disadvantages or meet their needs.

Example: Provision of specialist Learning Disability Liaison Nurses to help specifically cater for needs of LD pts on day case.

Example: Negotiation of higher tariff to allow for a longer appointment with optometrists to facilitate examination.

Human Rights Act 2008¹³

This legislation, with its emphasis on humanity, dignity, equality, respect and autonomy, applies equally to disabled people. The report of the Joint committee on Human Rights 2008 highlighted the widespread denial of fundamental human rights to people with learning disabilities.

The code of practice on rights of access beyond stating services should avoid being discriminatory; there is a positive duty to ensure that access should approximate that enjoyed by the rest of the public.



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Ophthalmologists should make reasonable adjustments to enable people with learning disability access to Eye Departments.

Table 7

Examples of adjustments to Eye Clinics to accommodate people with learning disability:

- The person visiting the clinic before the appointment, so they can see the waiting area, the room where the examination will take place and see the equipment to be used.
- Pre-admission visits to the ward and to meet the staff before the day of their operation.
- Extra time for appointments.
- Separate visits for vision testing and refraction from appointments with doctors. Ensuring the appointment is made at the time of day that best suits the patient – such as the first appointment in the morning, to avoid the person waiting for long periods.

Ophthalmologists are advised to read 'Equal access? A practical guide for the NHS: Creating a Single Equality Scheme that includes improving access for people with learning disabilities'¹⁴. This is a very helpful document with practical suggestions.

Equal Access to Screening

Increasingly screening programmes are being recognised as key in promoting ocular health in the general population. People with learning disability may miss out on these opportunities for many reasons, but often relating to communication. People with learning disability may not understand the purpose of the appointment, how to attend or book an appointment or be wary of any healthcare environment. Some screening programmes indirectly exclude those with learning disability, such as school vision screening services, which are only commissioned to visit mainstream schools.

An increasing number of schools for children with learning disabilities have visiting orthoptists providing screening services.



Routine Eye Tests for people with learning disability

People with learning disability should be enabled to have routine eye tests. People with learning disabilities may not self-refer when visual problems occur or may not know how to access services. If the sight loss is gradual, both the person affected, support staff and family carers may not notice changes in behaviour. Behavioural changes may be noted by carers but misinterpreted as deterioration in the person's general condition or attributed to aging, dementia, abuse or the learning disability itself. Many conditions amenable to treatment may be left to a stage where treatment is no longer useful. Treatable ophthalmic conditions such as cataract may result in months or years of needless handicap and distress.

Ophthalmologists should be aware of local services which provide support enabling people with learning disability gain access to eye tests.

These include referral to hospitals or specialist clinics for screening by an orthoptist, negotiating an enhanced fee for optometrists who have completed training in learning disability, direct referral to an ophthalmologist with an interest in learning disability or a multidisciplinary clinic with other specialists (in much the same way some trusts provide diabetic, uveitis or genetic clinics.)

http://www.lookupinfo.org/eye_care/services_in_your_area/optometrist_search.aspx

9. Supporting people with learning disability and low vision

The ophthalmologist plays a key role in signposting services for patients with learning disability and coordinating with social care networks to enable appropriate support to be provided. LookUp have produced forms which lay out in Easy Read format. These are useful for producing feedback to other agencies involved with people with learning disability.

CVI (Certificate of visual impairment)

Certification and registration is as important for people with learning disabilities as other patients. There is concern that people with learning disabilities and sight impairment are not being certified as being sight impaired or severely sight impaired. Certification and registration helps with accessing services and benefits and is an important step in collecting valuable statistical information. This Certification and registration is as important for people with learning disabilities as other patients. It alerts the local authority to a need to assess a person with a visual impairment. People with learning disabilities may not be registered, despite family and professionals knowing that the person was born with a visual impairment.



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It is important that ophthalmologists explain the certification process, or ask an eye clinic liaison officer (where employed) to do this. People do not need to be registered to receive help from local specialist services for blind and partially sighted people.

Rehabilitation officers for the visually impaired

Rehabilitation workers provide support to people with sight loss. They are usually employed by Local Authorities, local or national voluntary societies and organisations for blind and partially sighted people. Help from a rehabilitation officer for the visually impaired (ROVI) can make a substantial difference to people's quality of life. CVI registration is a 'passport' to these services and much can be achieved when they receive help from staff trained in visual impairment.

ROVIs are an essential link between health and social care. When working as part of a team supporting a person with complex needs rehabilitation workers can provide invaluable advice and skills to people who may be struggling with coming to terms with sight loss.

Referral to low vision services

People with learning disabilities can benefit from low vision services. However, they are rarely referred to low vision services. This is often because most low vision support is directed towards helping people read print or use complicated gadgets. As people with learning disabilities may not read or be able to use equipment, it is wrongly assumed that they will not benefit from a low vision assessment or have the ability to use any equipment recommended. However, many people with learning disabilities need low vision aids to watch TV or take part in leisure pursuits. Low vision assessment can also provide crucial advice on environmental adaptations to be made.

10. Promoting effective provision of services

Models of support for eye care

Until recently there was no clear model for the management of the general health needs of people with learning disability, particularly in adulthood.⁵ Whilst multi-disciplinary approaches to eye care for children with learning disabilities are increasingly common, services for adults may be patchy. Recent legislation in response to independent enquiries requires general practitioners to carry out an annual health check for people with learning disability which will include a prompt to suggest referral to an optometrist where there is concern about vision or the patient has not recently had an eye test.



Support for eye examinations and clinics

In the past, many optometrists complained that their training did not equip them to confidently assess adults with learning disabilities. New training courses are available.

http://www.rnib.org.uk/professionals/healthsocialcare/eyecareprofessionals/Pages/bridge_to_vision.aspx

Ophthalmic assessment is often most successful when care staff have been trained to support people having eye tests, clinic appointments and surgery. Professionals and family carers supporting the patient need to anticipate potential difficulties and work with eye care professionals to ensure the patient's co-operation.

Local initiatives provide a range of support to enable adults to access eye tests. Some areas identify which patients with learning disabilities should be supported to have an eye test with a community optometrist. Protocols ensure that people who might need a longer test and/or special approach are referred to hospitals or specialist clinics for screening by an orthoptist, working closely with an identified ophthalmologist. Some PCTs have negotiated an enhanced fee for optometrists who have completed training in learning disability.

In West Cumbria (Whitehaven), direct referral to an ophthalmologist with an interest in learning disability is available and utilised by paediatricians, GPs and optometrists¹⁵. The ophthalmologist, with the help of an orthoptist and nurse, runs a specific clinic once a month with a reduced number of scheduled slots compared to general clinics.

Separate clinic v special arrangements in routine clinic

Most services in the UK are need led and reactively orientated, making the most of sparse existing services. Children with developmental delay often pass from the hands of paediatricians to community paediatricians, GPs or learning disability trusts. Many young adults become "lost" into the community with little structured eye care unless disability registers are maintained.

Some NHS Trusts in the UK already run excellent joint Ophthalmic and Paediatric or Genetic clinics, often involving a multidisciplinary team that often includes an orthoptist or sometimes an optometrist. Although children with learning disabilities are being seen in such clinics, they may not be encouraged to attend when older since their diagnosis is confirmed and their bizarre behaviour may upsets smaller children. Services for adults are seldom structured.



Conclusion

Table 8

What every ophthalmologist can do

Adapted from Equal Access: a practical guide for the NHS¹

1. Communicate

- a. with the patient
- b. with the family and carers be prepared to listen to what they have to tell you about the patient and how best to care for them
- c. use easy English or Easy Read information

2. See the person not the disability

- d. take time to assess capacity

3. Be flexible - Consider how you may need to change your usual practice to best accommodate the patient

4. Involve people with learning disability in planning services

5. Discover what local services are available – use them to help you and direct your patients to them

People with Learning Disability remain vulnerable in terms of accessing and receiving equal treatment across the whole of healthcare. The high incidence of treatable visual loss in this group of patients can, in many instances, be remedied by offering and making accessible the options that are available to every other patient. Ophthalmologists play a key role in identifying treatable visual loss as a possible cause for altered behaviour. Working collaboratively, doctors, nursing and social staff should work towards enabling patients and carers to get the most out of ophthalmology services, make decisions in their best interests and improve not only visual outcomes but quality of life and independence.



Useful WebPages

- <http://www.library.nhs.uk/Eyes/ViewResource.aspx?resID=289966>
- <http://www.lookupinfo.org/>
- http://www.lookupinfo.org/you_and_eye_film/default.aspx
- <http://valuingpeople.gov.uk/index.jsp>
- www.mencap.org.uk
- www.rcn.org.uk/publications Dignity in health care for people with learning disabilities
- <http://www.sepho.org.uk/viewResource.aspx?id=12117>
- Department of Health South East Information Series Learning Disabilities
- <http://www.nursingtimes.net/improving-acute-care-of-people-with-learning-disabilities/583223.article> Patient Passports
- http://www.college-optometrists.org/en/professional-standards/Ethics_Guidelines/index.cfm College of Optometrists Code of ethics and guidelines for professional conduct. 24. Examining the adult patient with learning disabilities.



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References

1. Emerson E, Robertson J. Estimating prevalence of visual impairment among people with learning disabilities in the UK. Lancaster University: Centre for Disability Research, 2011.
2. Department Of Health. Valuing People: a new strategy for learning disability for the 21st century, 2001 <http://valuingpeople.gov.uk/index.jsp>.
3. Warburg M. Visual impairment in adult people with intellectual disability: literature review. *J Intellect Disabil Res* 2001 45:424-38.
4. Emerson E, Hatton C. People with Learning Disabilities in England. *CeDR Research* 2008.
5. Dutton G, McKillop E, Salokasimova S. Visual problems as a result of brain damage in children *British Journal of Ophthalmology* 2006;90:932-933.
6. LookUp. Information for Professionals. 2009 http://www.lookupinfo.org/eye_care_professionals/default.aspx.
7. LookUp. EasyRead Information, 2009 http://www.lookupinfo.org/easy_read_information/default.aspx.
8. Equality and Human Rights Commission. Equality Act, 2010 <http://www.equalityhumanrights.com/legislative-framework/equality-bill/>.
9. The Royal College of Ophthalmologists. Guidelines for Cataract Surgery, 2007 <http://www.rcophth.ac.uk/docs/publications/published-guidelines/FinalVersionGuidelinesApril2007Updated.pdf>
10. General Medical Council. Consent guidance: patients and doctors making decisions together 2008 http://www.gmc.org.uk/guidance/ethical_guidance/consent_guidance_index.asp.
11. Emerson E, Hatton C. Estimating the current need/demand for support for people with learning disabilities, in England. Lancaster, 2004
12. Department of Health. Healthcare for All: report of the independent inquiry into access to healthcare for people with learning disabilities, 2008 http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_099255.
13. Joint Committee on Human Rights. A life like any other? the Human rights of adults with learning disabilities, 2008 <http://www.publications.parliament.uk/pa/jt200708/jtselect/jtrights/40/40i.pdf>.
14. Department of Health. Equal access? A practical guide for the NHS: creating a Single Equality Scheme that includes improving access for people with learning disabilities, 2009 http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_109753.
15. Sellar W. Who should care for people with learning disabilities. *BMJ* 2000;321:1297.