The Royal College of Ophthalmologists

Ophthalmic Services Guidance

Executive summary

The management of visual problems in people with learning disabilities

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Ophthalmic Services Guidance

Introduction

This document summarises the key messages contained with the Royal College of Ophthalmologists guidance on Management of visual problems in people with learning disability. **The aim of this document is to demonstrate how simple changes to practice will enhance the quality of care provided to people with learning disability**. There are numerous personal accounts nationwide of ways in which ophthalmologists have been able to enhance the quality of life of people with learning disability. The impact of an intervention to improve sight should not be underestimated. This summary and accompanying chapter provide explanation and practical guidance for ophthalmologists in applying the principles of Mencap's "Getting it Right Charter[1]".

Table 1

Getting it Right

All people with a learning disability have an equal right to healthcare.

All healthcare professionals have a duty to make reasonable adjustments to the treatment they provide to people with a learning disability.

All healthcare professionals should provide a high standard of care and treatment and value the lives of people with a learning disability.

- **make sure that hospital passports are available and used**
- **make sure that all staff understand and apply the principles of mental capacity laws**
- **make sure every eligible person with a learning disability can have an annual health check**
- **provide ongoing learning disability awareness training for all staff**
- **listen to, respect and involve families and carers**
- **provide practical support and information to families and carers**
- **provide information that is accessible for people with a learning disability**

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Key facts about vision and people with learning disability[2]

There are about 1 million adults in the UK with a learning disability

- People with learning disabilities are 10 times more likely to have serious sight problems than other people. People with sever or profound learning disabilities are most likely to have sight problems.

- 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 a learning disability they know can see perfectly well.

- 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 often.

- People with learning disabilities are less likely to know of the availability of or how to access services in order to improve their visual function.

- Family carers, supporters and people with learning disability may be unaware of vision problems and that vision can be tested even if patients cannot speak or understand letters.

- People with learning disabilities have the same rights of access to NHS ophthalmic services as everyone else and legislation requires that reasonable adjustment should be made to meet their needs.

- 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 understanding and co-operation.

1. Identifying Key Issues

"Valuing People[3]" defines Learning Disability as the presence of

- A significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence)
- A reduced ability to cope independently (impaired social functioning)
- Problems which started before adulthood and have 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, 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 and outside mainstream education; those with a static or progressive condition.

Table 2

Major causes of learning disability in United Kingdom[4]

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

There are estimated to be over one million people in the UK with a learning disability. Adults with learning disabilities are 10 times more likely to be blind or partially sighted than the general population. The estimated prevalence of blindness and partial sight in the adult learning disabilities population is 9.3%[2]

There is a high rate of under detection of sensory impairment, much of which can be treated[5].

Sight is the key to learning, communication and movement. If someone already has problems with these areas, then a visual impairment may have more of an impact on them. A change in visual function may not be easily communicated by people with learning disability. It may manifest itself as a change in behaviour or withdrawal. Unless staff have experience in dealing with people with learning disability, these simple symptoms may not be recognised.

2. Challenges for the ophthalmologist

Identification

Patients with learning disability 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. Not all people with learning disability have an underlying diagnosis. **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.

Table 3

Ophthalmic Conditions prevalent in people with learning disability[4]

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

Signs and symptoms

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[6].

Table 4

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

Planning the visit

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

EasyRead leaflets are available to help the patient prepare for an eye test so they might be better able to anticipate what will happen[7]. 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 adjustments required as part of the Equality Act 2010.

Communication & Accessible information

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 disability[8].
People with learning disability 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 "EasyRead" format which uses plain language and illustrations to explain parts of the eye examination[7]. These should be used where appropriate, rather than providing the carer or patient with the standard clinic leaflet. Advice regarding using eyedrops or helping a patient learn to accept spectacles is available.

Table 5

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

Feedback

Lookup have produced feedback forms for health professionals to complete. These 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.

Consent and surgery

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**. 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 disability[9]. With adequate preparation and desensitisation successful and safe surgery is achieved in many patients.

"Did Not Attend" policies

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 a 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.

3. Improving & adapting services

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 based [8].

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 2010[10] This act will extend and replace the Disability Discrimination Act and came into force in October 2010.

A stand-alone clause of the Equality Act 2010 requires public bodies to provide accessible information. LookUp and Mencap provide EasyRead leaflets which will help people with learning disability understand and prepare for eye clinic[7].

Disability Discrimination Act 2005[11]

"Disability occurs when there is a physical or mental impairment which adversely affects an individual's capacity to carry out day to day activities. The adverse effect must be substantial and long term[11]".

Discrimination occurs if a service provider treats a disabled person less favourably for a reason related to the disability which cannot be justified by the act.

This Act imposes a duty on Healthcare Providers. **Ophthalmologists should make reasonable adjustments to enable people with learning disability access to Eye Departments.** Discrimination is particularly prohibited by refusing service, or provision of service on less favourable terms.

Table 6

Examples of adjustments which might be considered are:

- 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.

Disability Equality Duty[12]

The Disability Discrimination Act 2005[11] required public bodies to produce a Disability Equality Scheme. The aim is

1 eliminate unlawful discrimination against disabled people
2 eliminate disability related harassment
3 improve equality of opportunity
4 take steps to take account of disabilities, even where that involves treating them more favourably than other people
5 promote positive attitudes

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).

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'[13]. This is a very helpful document with practical suggestions.

Human Rights Act 1998

This legislation, with its emphasis on humanity, dignity, equality, respect and autonomy, applies equally to disabled people[14].

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.

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 capacity[15]
- GMC guidance on the Mental Capacity Act [16] (Consent guidance: patients and doctors making decisions together)

Models for Delivery

Until recently there was no clear model for the management of the general health needs of people with learning disability, particularly in adulthood. [17] 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.

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 referrals 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

CVI (Certificate of Visual Impairment) and Low Visual Services

Certification and registration is as important for people with learning disability as with other patients. People with learning disabilities may not be registered, despite family and professionals knowing that the person was born with a visual impairment. Registration is a 'passport' to services and rehabilitation workers can provide invaluable advice and skills to people with learning disability and their carers to help

them adapt to sight loss [18]. People with learning disabilities can benefit from low vision services : an inability to read should not preclude a referral[19]. Referral to a rehabilitation officer via adult social services may enhance the link between medical and social care and should be considered for those struggling with their vision even if not eligible for CVI registration.

4. Conclusion: What every ophthalmologist can do

Table 8

What every ophthalmologist can do
Adapted from Equal Access: a practical guide for the NHS[1]

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
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

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