
Community Eye Care for Adults & Young People with Learning Disabilities Pathway

September 2016

Background

It is important to define “learning disability” in order to differentiate it from mental health problems and ‘specific learning difficulties’ such as dyslexia and dyspraxia.

The definition currently used by the Department of Health in *Valuing People*¹ is: “A significantly reduced ability to understand new or complex information (reduced intelligence); a reduced ability to cope independently (reduced social functioning); which started before adulthood with a lasting effect on development.”

Mencap’s definition² is: “A learning disability is a reduced intellectual ability and difficulty with everyday activities - for example household tasks, socialising or managing money - which affects someone for their whole life.

“People with a learning disability tend to take longer to learn and may need support to develop new skills, understand complex information and interact with other people.

“The level of support someone needs depends on individual factors, including the severity of their learning disability.”

Learning disability should be perceived as a cognitive impairment making it harder to make sense of information. It is not mental illness (although due to a variety of factors mental illness is more prevalent in this group of patients). Most importantly for commissioners the very factors causing the learning disability may also affect normal visual development and people with a learning disability are more likely to need, but less likely to have, access to high quality eye care.

Frequency of sight testing

It is recommend that people with learning disabilities should have a sight test every two years or earlier if recommended by the optometrist. This is particularly important for people with learning disabilities because:

1. Under-reporting of eye and sight problems by people with learning disabilities either;
 - a. due to poor understanding of normal versus abnormal visual phenomena and
 - b. due to difficulties in communicating their concerns to carers or health professionals
2. The prevalence of cataract, keratoconus, tumours and even blepharitis is higher in people with learning disabilities and can manifest at an earlier age. This is especially true in people with Down's syndrome.

¹ www.dh.gov.uk Valuing people: A New Strategy for Learning Disability for the 21st Century. A white paper - DH

² www.mencap.org.uk

Purpose

The purpose of the Learning Disabilities Sight Testing Scheme is to increase the number of sight tests in patients diagnosed with learning disabilities.

People with learning disabilities (LD) 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.

Unfortunately many people with learning disabilities go through their lives unnecessarily disadvantaged because their carers may not know how to get appropriate eye tests for them. Carers and staff may wrongly assume that it is impossible to test the sight of people who have profound and multiple learning disabilities, or that nothing will be gained by such a test. Contrary to this belief, eyesight charities believe that two thirds of these patients can be seen in the community by an optometrist. However examination techniques need to be adapted, and a longer consultation time is required.

This commissioned service is a service with reasonable adjustments for someone who would not be able to use a standard eye test .This includes pre-appointment visits, completion of a functional vision assessment if needed, longer appointment time with an accredited practitioner in learning disabilities and feedback forms completed by the optometrist. The results of the examination are reported using the agreed appropriate format. Only accredited practitioners (optometrists or OMPs) would provide this service.

Inability to carry out an NHS sight test on a particular patient

In the rare cases that an optometrist does not feel able to provide a full NHS sight test to a patient with learning disabilities, they should, as in any other case, refer the patient to a colleague who is able to perform a sight test in line with this Pathway. The referral and reason for it should be noted and reported annually to the commissioning authority. Analysis of such information will enable commissioners to ascertain whether population health needs are being addressed or whether there are any access inequalities in the system which need to be addressed as part of local commissioning plans.

SeeAbility resources

SeeAbility, the national charity which provides specific support and information on eye care and vision for people with learning disabilities, has assisted with and endorses this Pathway and related information. A range of information resources to support the pathway are available on SeeAbility's website.

Where necessary, pre-visit support for patients should be provided as part of the pathway. This can be delivered by a range of people including family carers, support workers, Learning Disability Nurses, Rehabilitation Workers or Specialist Learning Disability Workers depending on the patient's requirements. For further information see SeeAbility's factsheet "Preparing for an eye examination".

SeeAbility's West Sussex eye 2 eye project sampled a wide range of groups and asked about the difficulties that were faced by people with learning disabilities when accessing eye care. The results clearly demonstrate that better preparation of the patients and practitioners significantly improves the outcome for people with learning disabilities, and this is reflected in the design of this Pathway.

This preparation may take the form of looking at booklets, pictures or videos explaining the procedure, or may entail visiting the examination room and meeting professionals and other staff in advance of the appointment date. This allows time for individuals with learning disabilities to understand what is involved in the procedure and often facilitates a better outcome for both patients and professionals.

This degree of preparation is rarely, if ever, needed for the general population who can more easily understand the examination processes, and discuss concerns with professionals. Two useful SeeAbility forms for this purpose are "Having an eye test" and "Telling the optometrist about me".

A very small number of people may have difficulty in complying or co-operating with a sight test in normal optometric practice or with standard equipment, due to the severity of their disability, other physical disability or challenging behaviour. These patients will be referred to a multi-disciplinary team at the Hospital Eye Service (HES), regional centre of excellence or other appropriate team.

Description

Patients may enter the pathway via several routes. They may be referred by their GP via their Annual Health Check (AHC), or by learning disability services, a carer or advocate, optometrist or OMP. Alternatively, they may self-refer. GPs should have a learning disabilities pack which contains all the relevant SeeAbility forms along with a list of accredited practitioners and other relevant agencies.

Patients who need the additional support in this Pathway should be able to choose from a list of practices and practitioners accredited to provide this community service, including domiciliary providers. Copies of the list will be distributed to GPs, optical practices, optometrists, dispensing opticians, relevant hospital services, social services and national and local charities.

The service should be available to anyone who is recognised by their GP as having a moderate to severe learning disability and are 14 years old or above who are on a local learning disability register as a person with a moderate to severe learning disability where this information is available.

The patient must be registered with a GP practice in the Cheshire and Merseyside Area and not registered with a GP anywhere.

The practitioner will ensure that the patient, and carer (if appropriate), is aware of the full range of local support services available and how to access them.

The service should follow the Pathway described in this document.

Domiciliary Service provision

The same principles apply to the provision of this service in a person's home or normal place of residence.

The domiciliary service should be made available where the patient is unable to attend a high-street practice unaided because of physical or mental illness or disabilities.

It is likely that individuals who require the domiciliary service will have more complex needs and challenging behaviour than those that are able to attend a high street practice, and consequently preparation with the patient is crucial. The carer should be advised by the practitioner about the requirement for a suitable room for the sight test and ways in which the patient can be prepared for the visit.

For domiciliary visits, it is essential that carers complete the 'Telling the Optometrist about me' form in advance so that the practitioner can ensure they have the most appropriate equipment with them.

During the sight test, the patient's normal carer should be present in the room to minimise the stress and to help with any communication issues. Their presence also provides reassurance for the practitioner if the patient has challenging behaviour.

In some cases, not all tests may be possible because of the nature of the patient's disabilities. The patient and/or carer will be consulted about this and the detail noted in the patient's follow-up report and record together with the reason for the test not being able to be performed on that particular patient.

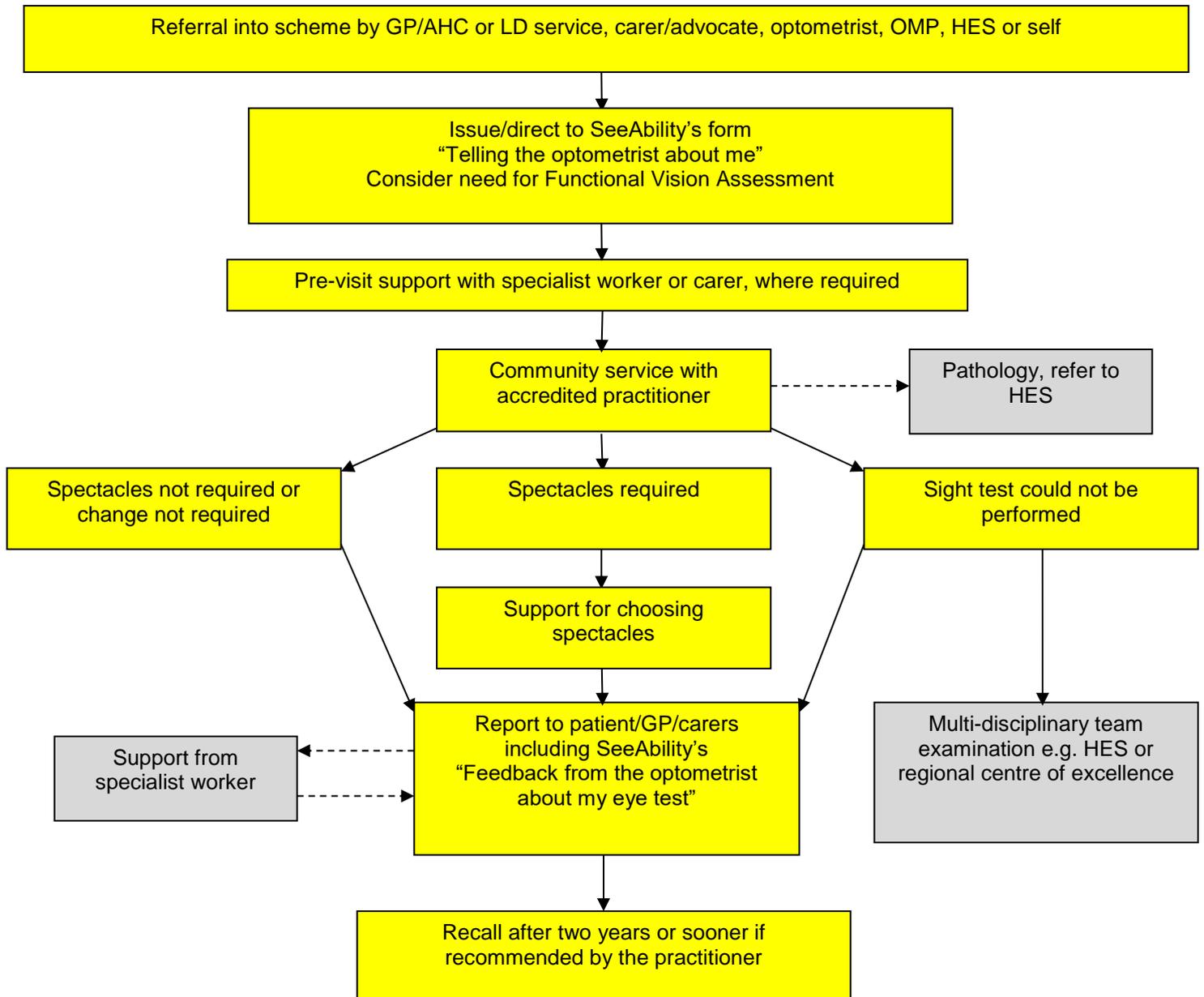
Accreditation and quality assurance

All optometrists have undergone basic training in the care of people with learning disabilities or limited communications. Most practitioners would not, however, consider themselves to be experts in this area and would need further advice and training to deliver this Pathway.

A WOPEC training and accreditation package has been developed by LOCSU in conjunction with SeeAbility and other appropriate bodies.

This Pathway should be delivered only by accredited practitioners, or those who are recognised by the commissioners as suitably experienced.

PwLD Pathway



LD: Learning Disability
AHC: Annual Health Check

The dotted lines in the flowchart above indicate alternative pathway depending on need.

Pathway

1. Many carers will be able to download and complete SeeAbility's pre-sight test "Telling the optometrist about me" form with the patient. For those that do not have this facility additional options should be available including collecting the form from the optometrist practice or having it sent to them. A list of accredited practices / practitioners can also be downloaded or made available. An appointment is made within 28 days and the pre-sight test form is sent to the chosen accredited practitioner prior to the sight test. The practitioner will review the pre-sight test form and ensure adequate measures are in place for the appointment to take place.
2. Consideration should be given to the need for a Functional Vision Assessment (FVA), especially where there are likely to be communications difficulties. This should be carried out by carers, specialist workers, learning disability nurses etc and the information provided prior to the sight test. A FVA designed specifically for carers and support staff (non eye care and vision professionals) is available. In addition some local primary healthcare services, now employ primary care liaison nurses/facilitators for people with a learning disability, in addition to community learning disability nurses (who often have a more specialist role)
3. Information should be available for the carer to help the patient prepare for the appointment in advance. For example the "Having an Eye Test" form from SeeAbility's Easy Read section. Additionally this may involve the patient visiting the practice on one or more occasions before the appointment day to familiarise them with the surroundings, the personnel and having a cover placed in front of each eye
4. Suitable equipment will be available e.g. Kay Pictures, Cardiff Cards, Sheridan Gardiner, attention grabbers (toys). The additional physical equipment required is not major; it is the willingness of the practitioner to offer a flexible and patient-centred approach that is the key to success.
5. Once the sight test has been carried out, any required spectacles will be dispensed as appropriate, with support as necessary. A GOS3 voucher will be issued where a patient is eligible. Where spectacles are prescribed, issue "Getting used to glasses" and "Looking after your glasses"
6. Where necessary the patient will be referred to the HES or other support services as appropriate e.g. where new pathology is found
7. SeeAbility's post-test "Feedback from the optometrist about my eye test" form must be completed and copies given to the patient, their GP and carer as well as being retained in the patient's records

Appendix 1

Information to be provided as part of the community service

Before the sight test

- SeeAbility's information service - Phone 01372 755 066 for information or advice, or view www.seeability.org which contains the following easy read information:
 - Having an eye test
 - Telling the Optometrist about me form

The website also contains information for carers and supporters, including a Functional Vision Assessment tool and other guidance on preparing for a sight test and supporting people to wear glasses.

After the sight test

General – for those with correctable refractive error

- "Feedback From The Optometrist About My Eye Test" form – ELECTRONIC auto produced
- SeeAbility's information service: phone 01372 755 066 for information or advice, or view www.seeability.org which contains the following easy read factsheets:
 - Choosing the right glasses
 - Looking after your glasses
 - Getting used to your new glasses
 - Wearing glasses

The website also contains information for carers and supporters on supporting people to wear glasses.

- How to get other support services

Low vision - for those with sight loss/low vision

- SeeAbility's information service: phone 01372 755 066 for information or advice, or view www.seeability.org which contains easy read factsheets and information for carers and supporters on eye conditions and treatment
- Eye Clinic Liaison Officer (ECLO)
- Learning disability liaison nurse (some hospitals have this resource)
- Independent Living Coordinator (ILCO)
- Local Sensory Impairment Team - Rehabilitation Officer for Visual Impairment
- Other local social services, what they can offer
- Local sight loss charities – you can search for contact details on www.visionary.org.uk
- Local Citizen's Advice Bureau – contact details required