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Ophthalmic Services Guidance

# Eye Care for Adults with Learning Disabilities

September 2015

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# 1 Key Messages

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- 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.
- Adults with learning disabilities are 10 times more likely to be blind or partially sighted than the general population.
- Six in 10 people with learning disabilities need glasses and often need support to get used to them.
- Assessing if people with learning disability have a vision problem can be undertaken as a functional visual assessment, rather than using a standard chart.
- People with learning disability (mild, moderate or severe) can benefit from spectacles, surgery, low vision aids and Certification of Visual impairment to support their activities of daily living. <sup>1</sup>

## 2 What is Learning Disability?

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Learning disability is defined as a significantly reduced ability to understand new or complex information, to learn new skills and reduced ability to cope independently <sup>2</sup>. The major causes of learning disability are shown in box 1.

*Box 1 Major causes of learning disability in United Kingdom <sup>3</sup>*

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

There are 1.2 million people with learning disabilities living in the UK <sup>4</sup>.

A recent confidential inquiry found visual problems to be present in 50% of those with premature deaths <sup>5</sup>. SeeAbility and RNIB funded a study published by Improving Health and Lives, the public health observatory for learning disability <sup>1</sup>. At present approximately 50,000 people with learning disabilities who are known to services in the UK have visual impairment (19,000 children, 31,000 adults); an additional 15,000 are blind (4,000 children, 11,000 adults). These numbers are likely to increase by 0.5% a year <sup>1</sup>.

Six in ten people with learning disability would benefit from glasses to help them perform activities of daily living

Large cohort studies from Europe have found visual impairment to be present in 12-22% of people in learning disability residential accommodation, with up to 79% having some visual problem (Box 2) [6,7](#).

*Box 2 Causes of Visual Impairment in People with Learning Disability [6,7](#)*

- Refractive surgery
- Amblyopia
- Strabismus
- Congenital cataract
- Acquired cataract
- Nystagmus
- Corneal problems
- Optic pathway abnormalities
- Perceptive and interpretive problems

### 3 Why people with learning disability need a different approach

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People with learning disability have a right to equal standards of health care by law, but evidence exists of inequality in accessing health services and continued unmet health care needs [8,9](#).

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 [10](#).

Reasonable adjustments include not just the removal of physical barriers, but changes to policies and to the whole care pathway to allow patients and carers to access services and receive equality of care [11,12](#).

A database of 'reasonable adjustments' made by health agencies is maintained by the learning disability public health observatory [13](#)

### 4 How to detect visual problems in someone with learning disability

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Recognising and identifying visual impairment is the first key stage in accessing services. This can be difficult as some patients with LD may have impaired communication abilities and be unable to attend regular eye checks. Some of the signs and symptoms of visual loss in a person with learning disability are shown in box 3.

Examples of behaviours associated with sight loss in people with a learning disability include:

- Anxiety in unfamiliar situations
- Unwillingness to venture out of their immediate environment
- Hesitancy on steps, at pavement edges or in poorly lit areas
- Depression
- Anger of frustration
- Eye poking or rubbing
- Reduction in social or domestic skills in participation
- Loss of interest in family, friends, TV or social activities
- Undue alarm at unfamiliar noises or when approached
- Self injurious behaviour <sup>15</sup>

Undertaking a traditional Snellen acuity test will not be appropriate for many patients with learning disability. Employing the skills of an orthoptist is often useful to assess vision using forced choice preferential looking techniques or picture/letter matching tests. Other measures such as contrast sensitivity can be useful in demonstrating reduction in visual function.

A functional visual assessment may also be useful in determining how the patient uses their vision day to day, and establish if there has been a change in visual function to support the diagnosis of onset of ocular pathology. An example can be found on the SeeAbility Website. <https://www.seeability.org/uploads/files/PDFs Books non Easy Read/Functional vision as sessment.pdf>

The RNIB have a devised a list of questions which can be addressed to the patient or carer <sup>16</sup>

- Has the person stopped a regular activity?
- Are they struggling to see the television?
- Are they finding it difficult to recognise people?
- Is there an increase in trips/falls?
- Does the person bump into furniture?
- Does the person overstep/are they hesitant at kerbs or stairs?
- Does the person knock items over at the table?
- Does the person consistently leave food on their plate?
- Does the person search for objects with hands?
- Does the person repeatedly clean their glasses or ask for them to be cleaned?
- Does the person move objects close to their face or move their face close to objects?
- Does the person get startled when approached unexpectedly?
- Does the person dislike or avoid going out on a sunny day?

## 5 Planning a clinic appointment

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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. Appendix B shows a list of reasonable adjustments which could be considered.

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 aware that people with learning disability may have a written health record that sets out how they prefer to be treated.

Many patients with learning disability have a written health record which contains key information. This may be called a 'patient or health passport', 'hospital book', or 'traffic lights system'. Passports provide key information such as communication and mobility issues, 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 happen <sup>15</sup>. 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).

## 6 "Did Not Attend" policies

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People with a learning disability are "vulnerable patients" and should be exempt from Trust DNA policies.

It is important to identify from referrals if a patient may be a vulnerable patient and consider offering another appointment. There may be instances where a person with a learning disability requires support to attend and this has not been made available so the patient is not brought to clinic. 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.

## 7 Communicating with patients and the team

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People with a learning disability may need extra time to understand or think about options presented to them.

Some patients with learning disability may need support from a carer or use of “Easy Read” leaflets which are available through the SeeAbility website.

Clinic letters should be copied to the patient and where appropriate to other members of the health and social care team. Often the GP has little day-to-day contact with the patient and advice about treatment needs to be communicated directly to the patient and carers.

The RNIB have published some tips on how to communicate with a person who has a learning disability and sight loss (Box 4 below)

### *Box 4 Learning Disability: Communication Tips 18*

- Talk to the person, not their supporter or carer.
- Speak slowly and clearly.
- Explain procedures in easy words: say what you are going to do then do it
- Explain and/or demonstrate the equipment to be used.
- Do not touch people without warning – give them time to communicate or show they have consented to being examined.
- Do not hurry people – they may get upset and less willing to co-operate.

## 8 Consent

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A full review of the Mental Capacity Act is available in the ophthalmic services folder.

Ophthalmologists should ensure that where possible, people with a 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 a learning disability from benefitting 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. A useful tool is presented below in Box 5.

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. With adequate preparation and desensitisation successful and safe surgery is achieved in many patients.

*Box 5 "Curb" took to assess capacity 19*

**C Communicate.** Can the person communicate their decision?

**U Understand.** Can they understand the information you are giving them?

**R Retain.** Can they retain the information given to them?

**B Balance.** Can they balance of use the information?

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.

If there is uncertainty around determining best interests, an IMCA, the person's advocate, and the local Community Learning Disability Team and key supporters' opinions should be sought.

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](http://www.dh.gov.uk/imca) and in Chapter 10 of the Mental Capacity Act (2005) Code of Practice.

## 9 Planning surgery

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A comprehensive list of reasonable adjustments and tips for successful surgery are shown in Appendix C.

Cataract is one of the most common reversible causes of visual loss in patients with learning disability 6,7. Anecdotally, there are many examples of adults with learning disability being excluded from eye services, of having cataract surgery declined because of concerns regarding eye rubbing, cooperation with post-operative drop regimes and post-operative infection. There is little published literature regarding outcomes and complications of surgery. Two reviews from Japan found significant improved in vision and quality of life for patient with learning disability following cataract surgery 20, 21. Whilst complications did occur in the minority of cases (post-operative uveitis, IOL dislocation, iris prolapsed) most were short-lived. Many of these could be avoided with modern surgical techniques and reasonable adjustments (see Appendix C).

Cataract surgery can offer sight improvements for many people, including those with learning disabilities.

Although outcomes can infrequently be measured in terms of improvement in Snellen acuity, the impact of restoring sight to a patient with learning disability cannot be overestimated. Sight is the key to independence, and in many cases cataract surgery reduces

the patients social care needs, improves their mobility, self-care skills and communication. Many barriers to surgery are imposed by health care teams and carers wishing to prevent causing distress for patients, before considering the possible benefits of surgery.

Cooperative working with anaesthetists, carers and community health facilitation teams to pre-empt problems and where possible allow patients the opportunity to desensitise to new experiences and surroundings can minimise distress and maximise the chance of a positive experience for all. Some patients may need additional support at home after the surgery. The majority of reasonable adjustments suggested do not require additional resources from within departments.

SeeAbility have an eye surgery support plan which can be used by hospital and community support teams to help plan surgery 22

## 10 Screening for eye disease in people with learning disability

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Vision screening is recommended for children at age 4-5 years and takes place in mainstream schools in most regions. However, not all healthcare regions fund the programme outside mainstream schools so children with a learning disability are less likely to be able to benefit. Reviews of visual problems in special schools in Scotland and Wales have been published and show that around 12- 20% of children in special education are visually impaired and 40-50% have a refractive error which is often uncorrected 23,24. Data from England (awaiting publication) shows a similar trend, with teachers and parents frequently unaware of a child's visual problems.

Some children with learning disability have difficulty processing images and parents report poor functional vision despite normal acuity and examination. Structured history taking can help elicit such processing deficits and provide strategies to minimise their impact on daily living and learning. 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.

### Diabetic Eye Screening Programme.

General Practice information systems show that people with learning disability are more likely to have diabetes, but less likely to be part of the eye screening programme 25. One audit found that although 91% of people with learning disability and diabetes had been offered screening, only 65% had an outcome recorded in the previous 12 months, and 26% had never undergone a successful screening visit 26.

Reasonable adjustments to facilitate successful screening have been published 26 and are shown in Appendix D.

## 11. Supporting people with learning disability and sight loss

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The RNIB have published advice for helping people with learning disability and sight loss (see Box 6).

Box 6 Environmental tips to help a person with a learning disability and sight loss

[www.rnib.org.uk/learningdisability](http://www.rnib.org.uk/learningdisability)

- Maximise use of natural light where possible
- Use vertical blinds to help control adverse effects of natural lighting such as glare and shadows
- Artificial and natural lighting levels should be consistent, even and controllable
- Make things bigger, brighter, bolder using good colour contrast
- Avoid highly patterned wallpaper, carpets and furnishings
- Avoid reflective surfaces where possible to minimise glare
- Encourage a clutter free environment to avoid trip hazards
- Use of individual recognisable tactile signifiers to aid location
- Use well contrasted and consistent pictorial and written signage

Certification of Visual Impairment for people with learning disability should not be overlooked. It is important that ophthalmologists explain the certification process, or ask an Eye Clinic Liaison Officer (ECLO) to do this.

The lack of a formal Snellen Acuity should not preclude a doctor from considering if the person could be certified as sight impaired.

Where it is not possible to achieve a Snellen acuity measure, doctors should consider if the patient's poor vision is contributing to their lack of independence and need for support in performing activities of daily living.

### **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 the sight impaired. 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 to come to terms with sight loss.

## Referral to low vision services

People with learning disabilities can benefit from low vision services.

As people with learning disabilities may not read, it may be wrongly assumed that they will not benefit from a low vision assessment or may not have the ability to use any equipment recommended. However, low vision services offer not only low vision aids in many accessible formats, they provide advice and environmental modifications from which people with learning disabilities can benefit greatly to improve their enjoyment of TV, to help with food/drink preparation and to make mobility in the home easier and safer.

The Royal College of Ophthalmologists



**Quality Standards Development Group**

**and**

**Vision 2020 UK Learning Disabilities Group**

## **Quality Standards for Services for Patients with Learning Disabilities**

### **Introduction**

There are a number of reasons for wanting to know how well a clinical service is working. A commissioning organisation or a regulatory body may want evidence of quality to inform a commissioning decision or as part of an inspection. A department may wish to know how well it is doing in comparison with another department or whether it is improving, standing still, or deteriorating over a period of time. There are many possible ways of measuring quality ranging from opinions of service users and staff to hard measures of outcome such as mortality. However, good measures of quality may be defined as ones which ask questions which discriminate accurately between a service which is serving its patients well and one which is failing its patients.

The College's Quality Standards Group has produced a suite of simple self-assessment tools in draft form for the following clinical services: cataract, glaucoma, diabetic retinopathy, children and young adults, oculoplastics, age-related macular degeneration (AMD) and vitreoretinal surgery. The tools do not attempt to assess every aspect of each service, but focus on areas where problems are likely to show if the service is under stress. Very few clinical services will achieve a perfect score, so the questionnaires can be used as quality improvement tools as well as snapshot audit tools.

Please send feedback to [Beth Barnes](#), Head of Professional Standards.

Document supported by:



1. There is a nominated lead for Learning Disability who can be contacted by the community team to help coordinate care (this could be a consultant, a senior nurse or the Eye Clinic Liaison Officer)

EFFECTIVENESS 50%    PATIENT EXPERIENCE 50%

YES (score 1)     NO (score 0)     UNABLE TO ANSWER (score 0)

2. There is a mechanism by which patients and/or carers can alert reception staff that the patient may require reasonable adjustments (eg patient alert card)

EFFECTIVENESS 50%    PATIENT EXPERIENCE 50%

YES (score 1)     NO (score 0)     UNABLE TO ANSWER (score 0)

3. Clinical staff are proactive in asking patients or carers for their patient health passport, traffic light or hospital book which outlines communication and healthcare preference

SAFETY 50%    EFFECTIVENESS 50%

YES (score 1)     NO (score 0)     UNABLE TO ANSWER (score 0)

4. The department works with patients and carers to offer reasonable adjustments (eg appointment times, familiarisation visit, quiet area to wait, minimal waiting time)

EFFECTIVENESS 50%    PATIENT EXPERIENCE 50%

YES (score 1)     NO (score 0)     UNABLE TO ANSWER (score 0)

5. Patients undergo visual assessment appropriate to their ability, in particular considering an orthoptic or functional visual assessment.

EFFECTIVENESS 50%    PATIENT EXPERIENCE 50%

YES (score 1)     NO (score 0)     UNABLE TO ANSWER (score 0)

6. Patients are enabled to consent for examination (for example dilating drops) and treatment where possible (eg easyread information, clear explanation, additional time, support from advocate)

SAFETY 50%    PATIENT EXPERIENCE 50%

YES (score 1)  NO (score 0)  UNABLE TO ANSWER (score 0)

7. Concerns around consent does not preclude patients from benefitting from surgical intervention (eg family and carers, best interest meeting and IMCA or AWIA (Scotland), are involved as appropriate)

SAFETY 50%

PATIENT EXPERIENCE 50%

YES (score 1)  NO (score 0)  UNABLE TO ANSWER (score 0)

8. The department does not routinely discharge vulnerable patients who “DNA”.

SAFETY 100%

YES (score 1)  NO (score 0)  UNABLE TO ANSWER (score 0)

9. Patients with low vision are offered support (eg ECLO referral, CVI, LVA referral, signposted to community services and supported in adjusting to spectacle wear where necessary).

SAFETY 50%

EFFECTIVENESS 50%

YES (score 1)  NO (score 0)  UNABLE TO ANSWER (score 0)

10. Outcomes of clinic appointments are communicated in a manner appropriate for the patient and, with consent, to all members of the patient’s healthcare team.

SAFETY 50%

EFFECTIVENESS 50%

YES (score 1)  NO (score 0)  UNABLE TO ANSWER (score 0)

Total Score:

Balance of Questions

SAFETY 35% PATIENT EXPERIENCE 30% EFFECTIVENESS 35%

## **Appendix B Reasonable adjustments which can be made to facilitate access to eye clinic for patient with a learning disability.**

### **Making the appointment**

Administration staff should be made aware that changes can be made

- 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.
- Early appointment when clinic less busy
- Particular time of day to suit carer/patient depending on cooperation
- Kept waiting as little as possible (notes passed straight to doctor or nurse)
- Visit to the department prior to appointment
- Split visits (to have VA, to see doctor) to reduce time in eye clinic
- No eye drops or do eye drops at home first

### **Patient information**

- Hospital providing information on what sort of tests might be included in visit to clinic so patient can be prepared
- Carer providing information about patient medical condition and patient's visual function
- Carer and patient to inform doctor of patient attitude to being touched, communication etc

### **Arriving at clinic**

- Reception staff aware of adjustments which can be made
- Nursing staff alerted as patient checks in – quiet area available, if referral had not indicated a learning disability, decision made about type of vision test suitable
- Medical staff alerted so can prioritise patient and minimise wait, get equipment together, adjust room so suitable for patient

### **Visual assessment**

- Snellen, Kays, matching
- Orthoptic colleagues to assess vision
- Functional assessment - Why is there concern about vision? (see later)

### **Examining the patient**

- Explain what is going to happen
- Warn patient before turning lights off
- Warning patient before they are touched
- Inventive ways of achieving what is needed
- Alternative ways of checking eye pressure
- Minimal use of eye drops/appropriate preparation

### **Providing feedback/communication**

- Copy of the GP letter to be sent to patient and caring team
- Utilise SeeAbility's optometrist feedback form
- Provide information leaflet/easy read information
- Consider another appointment to come back and ask more questions

**Appendix C A list of stages in the pathway of cataract surgery for a patient with learning disability and the reasonable adjustments which can be offered to overcome the barriers or issues which frequently arise.**

Pathway	Reasonable adjustment
Referral and appointment making	<p>Identify learning disability on referral letter</p> <p>Offer pre appointment visit to the department</p> <p>Liaise with patient and carer to ensure appointment on a day and time carer is available to attend</p>
On the day of the appointment	<p>Offer a quiet area for the patient to wait</p> <p>Alert staff to a patient arrival to minimise wait</p> <p>Avoid patient joining system of queues for tests which may not be appropriate</p>
Assessment in clinic	<p>Visual assessment appropriate to patients ability e.g. with orthoptist, functional visual assessment</p>
Communication and discussion	<p>Offer EasyRead leaflets</p> <p>Copy letter to patient, carers GP and community LD team</p>

## Pre-assessment

Pre-visit	Consider offering patient and carer a visit to the pre-assessment unit on the day of listing so they can experience the environment before any investigations are undertaken
Biometry	Consider allowing extra time or extra visits to complete biometry Consider allowing the patient to watch while biometry measurements taken on e.g. carer, so they understand what will happen
Involve anaesthetists	It is often helpful to arrange for the anaesthetists to meet the patient and carer before the day of surgery to anticipate issues such as posture, airway access management and venous access
Pre-operative investigations	In some cases, pre-operative screening investigations may not be possible. This should also be discussed with the anaesthetist
Venous Thromboembolism prophylaxis	Consider if omitting VTE is an appropriate reasonable adjustment
Choosing a bed	If the patient has adequate understanding, consider allowing them to choose the bed space to which they will be admitted on the day of surgery, and to meet the nurse who will be on duty if possible
Desensitisation to post-operative treatment	Offering the patient a shield to explore and practice wearing at home avoids the distress of this being encountered for the first time after surgery. The patient and carer can also be issued with a bottle of artificial tears to practice drops instillation.

### *The day of surgery*

Morning list	Consider if the patient will be able to tolerate fasting during the day for pm list
Place on list	Often being first on list minuses delay Consider placing later in morning if arrival at hospital by 07:30 is problematic
Pre-medication	Consider if the patient would require sedation prior to anaesthetic and that this may alter placement on theatre list
Pre-op drops	Consider if these can be installed after anaesthetic induction
Theatre gowns	Consider if the patient can remain in their own clothes

### *Intra operative*

Unable to undertake biometry (eye measurements to decide on lens power)	Biometry can be performed under GA
Pupil/dilation management	Consider asking carers to instill longer action drops
Management of post-operative inflammation	Consider desensitisation programme prior to surgery (See SeeAbility eye surgery support plan)
Wound management	Consider vicryl suture to wound to minimise risk from rubbing or coughing in recovery period
Post-operative refractive outcome	Consider leaving the patient slightly myopic if patient less likely to tolerate spectacles post-operatively

*Post-operative care*

Recovery	<p>Consider a quiet area</p> <p>Inform other patients that patient may sound in distress but is actually just in unfamiliar surroundings</p> <p>Allow carer to be present in recovery as patient wakes so they see a familiar face</p>
Post-operative drops	<p>Consider a twice daily regime, which can be instilled while patient is asleep</p> <p>Avoid struggling to put in drops – pressure on the eye is more likely to cause harm than omitting drops</p>
Post-operative follow-up	<p>Offer an appointment the day following surgery should the carer have any concerns, although if surgery is straight forward follow-up can occur between one and four weeks as usual</p>

## **Appendix D Reasonable Adjustments to consider in diabetic retinopathy screening.**

Reasonable adjustments for people with learning disability could include the following (27)

### **Highlighting the disability**

In order for reasonable adjustments to be offered, the patient's disability needs to be known to those offering a service. Ensuring all adults with learning disability are documented as such would facilitate engagement with the patient and carers to offer such adjustments

### **Promoting access**

Avoid excluding patients from the service solely on the basis of their learning disability without exploring what adjustments might be made to allow the patient to undergo screening.

### **Information**

Easy Read leaflet included with appointment letter for carer and patient so they can prepare for the examination and know what to expect. This may help to reduce "DNA" rates.

### **Desensitisation**

Arranging a pre-appointment visit to screening clinic to familiarise the patient with the new environment and equipment.

### **Additional time**

Offering a double appointment to patients with learning disability can enhance the likelihood of a successful screen and allow both the patient and the screener additional time to make adjustments.

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