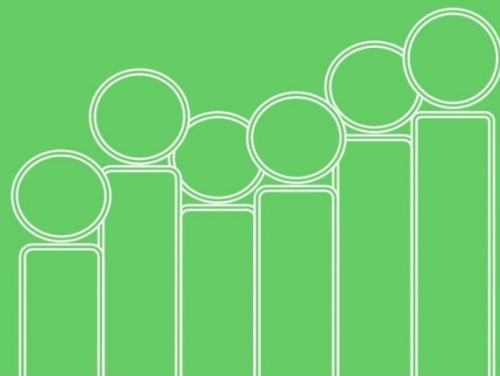


# Making Reasonable Adjustments to Eye Care Services for People with Learning Disabilities

Sue Turner, Stephen Kill & Eric Emerson



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## About the Authors

**Sue Turner** initially trained as a nurse for people with learning disabilities in Bristol. She has worked within training, as a Nurse Advisor in Gloucestershire, and has managed a variety of services for people with learning disabilities in Gloucestershire and Bristol including community learning disability teams. Sue was the Valuing People Lead for the South West Region for four and a half years, initially job sharing the role with Carol Robinson. During this time, Sue developed the health network in the South West and introduced the health self-assessment tool to the region. She later worked closely with the Strategic Health Authority on its implementation. Sue is now leading on the Improving Health and Lives project for the National Development Team for Inclusion.

**Stephen Kill** has worked with people who have sight loss and multiple disabilities for 17 years. Stephen qualified as a Rehabilitation Officer for Visually Impaired People in 1995 having studied for his Diploma in Rehabilitation Studies at the University of Central England in Birmingham. He has worked as a community-based Rehabilitation Officer with Surrey Association for Visual Impairment (SAVI) and in 2000 joined SeeAbility as a Senior Rehabilitation Practitioner where he worked with people with multiple disabilities and sight loss in residential, day service and supported living settings. In 2006, Stephen joined SeeAbility's eye 2 eye Campaign team to transform eye care and vision for people who have learning disabilities across the UK. Stephen is currently eye 2 eye Manager for London and the South East.

SeeAbility is a registered charity which enriches the lives of people with sight loss and multiple disabilities. SeeAbility specialise in supporting young people and adults who have a diverse range of multiple disabilities including sight loss, learning and physical disabilities and degenerative conditions. We are the leading experts in this field. SeeAbility provide vital resources to support people throughout the UK with learning disabilities who are 10 times more likely to have a sight problem but may not be able to communicate this and are least likely to have access to an appropriate sight test.

**Eric Emerson** is Co-Director of the Improving Health and Lives Learning Disabilities Observatory. Eric is also Professor of Disability & Health Research at the Centre for Disability Research, School of Health & Medicine, Lancaster University and Professor of Disability Population Health at the Centre for Disability Research and Policy, University of Sydney.

**Acknowledgements:** We would like to thank all those who contributed to this report by sending us examples of reasonable adjustments and good practice.

## Easy read summary



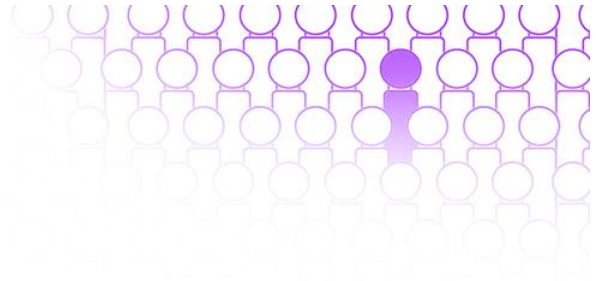
People with learning disabilities are more likely to have a sight problem than other people.

They are less likely than other people to get the right help and support with eye care.

The law says public services should put 'reasonable adjustments' in place to help people with learning disabilities use them. This means they need to change their services so they are easier to use.

This report has lots of information about reasonable adjustments in eye care services. Professionals and carers can use them to get better eye care services for people with learning disabilities.

The report also has some examples of how local services have put reasonable adjustments in place so that people with learning disabilities can use eye care services.



## Introduction

This report is the third in a series of reports written by the Learning Disabilities Public Health Observatory (LDPHO: [www.ihal.org.uk](http://www.ihal.org.uk)) focusing on reasonable adjustments in a specific service area. The aim of these reports is to make it easier for people to find and use reasonable adjustments, and to share good practice regarding implementation of reasonable adjustments. The report has been written with SeeAbility, because of their expertise in this area. Other examples of reasonable adjustments in eye care services were sent to us following a request to the Janet Cobb network ([janet@jan-net.co.uk](mailto:janet@jan-net.co.uk)). We also looked at a number of websites (see resources section for details).

The LDPHO is one of the small number of specialist public health observatories that cover England. It was established by the Department of Health in April 2010 in response to a recommendation made by the *Michael Inquiry* into access to health care for people with learning disabilities.<sup>1</sup> The LDPHO is a partnership between the North East Public Health Observatory (the contract holder), the Centre for Disability Research at Lancaster University and the National Development Team for Inclusion.

Learning disability refers to a significant general impairment in intellectual functioning (typically defined as having an IQ of less than 70) that is acquired during childhood.<sup>2</sup> In England approximately 1.2 million people have learning disabilities (290,000 children, 900,000 adults).<sup>3</sup>

People with learning disabilities have significantly higher rates of mortality and morbidity than their non-disabled peers.<sup>3-7</sup> The importance of actively addressing the health inequalities experienced by people with learning disabilities has been highlighted by recent reports from: the Disability Rights Commission;<sup>5</sup> Sir Jonathan Michael's independent inquiry into the healthcare of people with learning disabilities;<sup>1</sup> the Parliamentary, Health Services and Local Government Ombudsman;<sup>8</sup> the House of Lords and House of Commons Joint Committee on Human Rights;<sup>9</sup> the Department of Health;<sup>10-14</sup> and Mencap.<sup>15,16</sup>

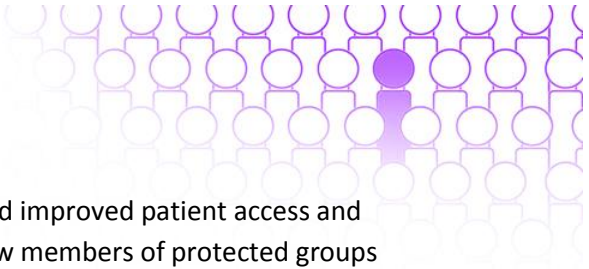
It is a statutory requirement under the Equality Act 2010 and the NHS and Social Care Act 2008 that public sector agencies make 'reasonable adjustments' to their practice that will make them as accessible and effective as they would be for people without disabilities. Reasonable adjustments include removing physical barriers to accessing health services, but importantly also include making whatever alterations are necessary to policies, procedures, staff training and service delivery to ensure that they work equally well for people with learning disabilities.<sup>17-21</sup> A database of 'reasonable adjustments' made by health agencies is maintained by the LDPHO.<sup>22a</sup>

This legal duty for health services is 'anticipatory', meaning that health service organisations are required to consider in advance the adjustments people with learning disabilities will require, rather than waiting until people with learning disabilities experience problems using health services.

The recent NHS Equality Delivery System provides a framework of questions for all parts of the health service in relation to all protected groups. Its recently published 'Grades Manual' sets out four overarching goals and invites NHS organisations to identify evidence about their progress in

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<sup>a</sup><http://www.improvinghealthandlives.org.uk/adjustments/>



relation to these.<sup>23</sup> The first two (better health outcomes for all, and improved patient access and experience) ask healthcare organisations to look for evidence of how members of protected groups (the term used in the Equality Act) are faring in terms of their health and their use of health services. Answering these questions comprehensively, systematically and regularly requires that health service information systems identify people in the protected groups so comparisons can be made. In addition to exploring substantive questions that should be asked, the Equality Delivery System also discusses the need to discuss the ways arrangements are made to do this for members of all the protected groups, with the people in those groups themselves.

More generally, the importance of strategies to reduce health inequalities taking account of the specific situation and characteristics of high risk and marginal groups (such as people with learning disabilities) has been highlighted by the Health Select Committee, the National Institute for Clinical Excellence, The Marmot Review and the on-going World Health Organisation review of strategies to address health inequalities in Europe.<sup>24-27</sup> The UK has also entered into international obligations to progressively realise the right to health of people with disabilities and to take specific measures to address the health inequalities faced by vulnerable groups such as people with learning disabilities.<sup>28,29</sup>

## Visual impairments and people with learning disabilities

Reviews of existing scientific evidence suggest that people with learning disabilities are between 8 and 200 times more likely to have a visual impairment than their non-disabled peers.<sup>30,31</sup> Research has also suggested that: (1) people living independently or with family are significantly less likely to have had a recent eye examination than people living with paid support staff;<sup>32</sup> (2) carers of people with learning disabilities frequently fail to identify sensory impairments, including cerebral visual impairment.<sup>33-35</sup>

In 2010 RNIB and SeeAbility commissioned the LDPHO to address two questions. How many people with learning disabilities in the UK are likely to have visual impairments? How will this number change over the coming decades? Our resulting report<sup>36</sup> suggested that:

- 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);
- There may be an additional 44,000 adults with learning disabilities and visual impairment and 11,000 with learning disabilities and blindness who are not known to adult health or social care learning disabilities services;
- Overall, people with learning disabilities are 10 times more likely to have serious sight problems than other people. People with severe or profound learning disabilities are most likely to have sight problems.
- 6 in 10 people with learning disabilities need glasses and often need support to get used to them.

With regard to specific refractive errors, we estimated that

- 32,000 children with learning disabilities have myopia ('shortsightedness' resulting in difficulty focusing on more distant objects) and 55,000 hyperopia ('longsightedness' resulting in difficulty focusing on closer objects) ( $\geq 3D$ )<sup>b</sup>
- 11,000 adults with learning disabilities known to services have severe myopia and 8,000 severe hyperopia ( $\geq 5D$ )

We also predicted that all of these figures will rise by approximately 0.5% each year over the next two decades.

## Eye care services and people with learning disabilities

People with learning disabilities who are eligible for a health check under the Directed Enhanced Service (DES) scheme<sup>37</sup> should have a health check based on the Cardiff Health Check, which includes a section on difficulties with vision. Any problems identified should be noted in the Health Action Plan, and appropriate steps should be taken to address the issue. However, only 53% of people eligible for a health check received one last year,<sup>38</sup> and we do not know how comprehensive they were. Therefore it is vital that family carers and support staff ensure that people with learning disabilities get regular eye tests and are supported to access the full range of eye care services in the same way as their non-disabled peers. A number of resources to enable access are signposted in the resources section below.

Good eye care should start in childhood. A recent report on children in special schools in Wales found that over one third of pupils had never had a sight test, despite it being known that children and young people attending special schools are known to be at greater risk of visual impairment than children in mainstream schools.<sup>39</sup>

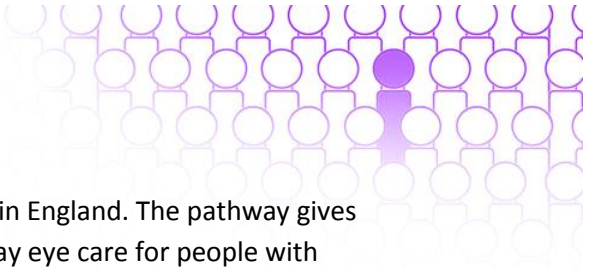
In order to plan good eye care services for people with learning disabilities, it will be important to include information about people with learning disabilities who have visual impairments in the Joint Strategic Needs Assessment (JSNA). A Public Health Indicator for preventable sight loss is being introduced as part of the Public Health Outcomes Framework in England.<sup>c</sup> The indicator will monitor the major causes of preventable sight loss in adults from April 2013. Public Health England, the organisation responsible for this Framework, will assess how many people are certified as sight impaired (partially sighted) or severely sight impaired (blind) and have lost their sight from one of the three major causes of preventable sight loss: glaucoma, age-related macular degeneration and diabetic retinopathy. The indicator comes with a briefing which is available at [www.commissioningforeyecare.org.uk](http://www.commissioningforeyecare.org.uk). The website includes a JSNA template which has some information on people with learning disabilities.

The Local Optical Committee Support Unit (LOCSU) has developed a Community Eye Care Pathway for Adults and Young People with Learning Disabilities. The pathway has been developed in conjunction with Mencap and SeeAbility, and is based on established, successful, learning disability

<sup>b</sup>Optometrists measure the focusing power of the eye using dioptres (D), a technical term for how strong a lens would have to be to give normal vision. In these estimates, myopia and hyperopia is defined in terms of needing a lens of at least three dioptres to produce normal vision, severe myopia and hyperopia is defined in terms of needing a lens of at least five dioptres to produce normal vision.

<sup>c</sup>[www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_132358](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_132358)





services provided by community optometrists in a number of areas in England. The pathway gives Local Optical Committees the basis for a proposal to improve the way eye care for people with learning disabilities is delivered in their local area<sup>d</sup>[www.locsu.co.uk/enhanced-services-pathways/community-eye-care-pathway-for-adults-and-young-pe](http://www.locsu.co.uk/enhanced-services-pathways/community-eye-care-pathway-for-adults-and-young-pe)

SeeAbility has a national database of optometrists and opticians which includes key information about the practice and the facilities they have available for people with learning disabilities. For further information see

[www.seeability.org/eyecare\\_hub/optometrists\\_in\\_your\\_area/optometrist\\_search.aspx](http://www.seeability.org/eyecare_hub/optometrists_in_your_area/optometrist_search.aspx)

Please also see the College of Optometrists guidance on examining adults with learning disabilities:

[www.college-optometrists.org/en/utilities/document-summary.cfm/9FE6B6A0-D054-4F99-96D71008D858A59E](http://www.college-optometrists.org/en/utilities/document-summary.cfm/9FE6B6A0-D054-4F99-96D71008D858A59E)

## About SeeAbility

SeeAbility is a registered charity which enriches the lives of people with sight loss and multiple disabilities. SeeAbility currently provides support services in the South West and South East of England. Launched in 2005, SeeAbility's eye 2 eye Campaign operated community development projects across England, and in 2007 launched a web based information service focussing on eye health and vision for people who have learning disabilities. SeeAbility's eye 2 eye Campaign has worked with people with a learning disability, their family carers, and health and social care staff including eye care professionals to transform eye care and vision for people who have learning disabilities. SeeAbility's website ([www.seeability.org](http://www.seeability.org)) has a wealth of free resources designed to support people with learning disabilities to prepare for and attend an eye test, to wear glasses, to have surgery and treatment and to access subsequent support services. The "My Eye Care" section has easy read information for people with learning disabilities.[www.seeability.org/myeyecare/](http://www.seeability.org/myeyecare/). The "Eye Care Hub" has further information for carers and supporters [www.seeability.org/eyecare\\_hub/](http://www.seeability.org/eyecare_hub/)


## Consent and capacity

Consent must be sought prior to any investigation or treatment. Some of the resources detailed below are designed to enable people with learning disabilities to make informed decisions about their eye care. The Mental Capacity Act 2005 sets out the law regarding capacity and consent and is underpinned by five key principles which must be considered when assessing capacity:

- A person must be assumed to have capacity unless it has been clearly established that they lack capacity regarding the specific decision under consideration at that point in time.
- A person is not to be treated as unable to make a decision unless all practicable steps to help him/her to do so have been taken without success.
- A person is not to be treated as unable to make a decision merely because he/she makes what is considered to be an unwise decision.

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<sup>d</sup>[www.locsu.co.uk/enhanced-services-pathways/community-eye-care-pathway-for-adults-and-young-pe](http://www.locsu.co.uk/enhanced-services-pathways/community-eye-care-pathway-for-adults-and-young-pe)

- 
- An act done, or decision made, under the Mental Capacity Act for or on behalf of a person who lacks capacity must be done, or made, in his/her best interests.
  - Before the act is done, or the decision is made, regard must be had to whether the purpose for which it is needed can be as effectively achieved in a way that is less restrictive of the person's rights and freedom of action.

Where an individual is not considered to have capacity to consent, a 'best interest' meeting may need to be held. There is information on capacity and consent on the SeeAbility website at:

[www.seeability.org/myeyecare/eye\\_operations/consent.aspx](http://www.seeability.org/myeyecare/eye_operations/consent.aspx)

There is a helpful guide for family carers on the Mental Capacity Act at: [www.hft.org.uk/Supporting-people/family-carers/Resources/MCA-guide/](http://www.hft.org.uk/Supporting-people/family-carers/Resources/MCA-guide/)

## Resources

### The SeeAbility website

The SeeAbility website [www.seeability.org](http://www.seeability.org) has a wide selection of helpful information. The “My Eye Care” section has easy read information for people with learning disabilities which includes information on:

- Eye health
- Eye sight tests and wearing glasses
- Eye operations
- Eye conditions

The “Eye Care Hub” has further information for carers and supporters  
[www.seeability.org/eyecare\\_hub/default.aspx](http://www.seeability.org/eyecare_hub/default.aspx)

In addition to the above, the following sub-sections include some examples from practice, many of which reference the use of SeeAbility resources and links to other easy read resources, which can be found on; the Easyhealth site: [www.easyhealth.org.uk](http://www.easyhealth.org.uk); the picture of health site: [www.apictureofhealth.southwest.nhs.uk](http://www.apictureofhealth.southwest.nhs.uk); and the LDPHO reasonable adjustments database [www.ihal.org.uk/adjustments/](http://www.ihal.org.uk/adjustments/).

Please note, some resources may be available from more than one site, but we have only included one link per resource, and we have only included resources that are free to download, although the Easyhealth site includes resources you can buy.

### Reasonable adjustments regarding eye care services

Looking after your eyes	<p><b>Looking after your eyelids</b>            A leaflet by the South Staffordshire and Shropshire Healthcare NHS foundation trust  <a href="http://www.easyhealth.org.uk/sites/default/files/looking_after_your_eyelids_0.pdf">www.easyhealth.org.uk/sites/default/files/looking_after_your_eyelids_0.pdf</a></p> <p><b>10 times more likely to have sight problems</b>            A film which explains the important messages about eye care.  <a href="http://www.seeability.org/myeyecare/eye_health/sight_loss_messages.aspx">www.seeability.org/myeyecare/eye_health/sight_loss_messages.aspx</a></p>
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Information on visual impairments for people with learning disabilities	<p><b>Information for people with learning disabilities about visual impairments</b>            A leaflet by the Information for All team at the Norah Fry Research Centre and the Royal National Institute for the Blind Multiple Disability Services  <a href="http://www.easyhealth.org.uk/sites/default/files/information_about_visual_impairments.pdf">www.easyhealth.org.uk/sites/default/files/information_about_visual_impairments.pdf</a></p>
Information on visual impairments	<p><b>Visual impairment and learning disability</b>            A leaflet by Mencap  <a href="http://www.easyhealth.org.uk/sites/default/files/Visual%20impairment%20and%20learni">www.easyhealth.org.uk/sites/default/files/Visual%20impairment%20and%20learni</a></p>

for family carers/paid staff.	<p><a href="#">ng%20disability.pdf</a></p> <p><b>How to spot eye problems</b> Guide to spotting eye problems in people with learning disabilities. Kingston PCT <a href="http://www.improvinghealthandlives.org.uk/adjustments/index.php?adjustment=146">www.improvinghealthandlives.org.uk/adjustments/index.php?adjustment=146</a></p>
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## Going to the optometrist

Information for the optometrist	<p><b>Telling the optometrist about me</b> An Easy Read form to help someone prepare for an eye test with an optometrist <a href="http://www.seeability.org/myeyecare/eye_test/telling_optom.aspx">www.seeability.org/myeyecare/eye_test/telling_optom.aspx</a></p>
Having an eye test	<p><b>Getting your eyes tested</b> A leaflet by the North and West Belfast Health and Social Services Trust <a href="http://www.easyhealth.org.uk/sites/default/files/Getting%20your%20eyes%20tested.pdf">www.easyhealth.org.uk/sites/default/files/Getting%20your%20eyes%20tested.pdf</a></p> <p><b>Eye tests for adults</b> A film by NHS Choices <a href="http://www.easyhealth.org.uk/content/eye-tests-adults">www.easyhealth.org.uk/content/eye-tests-adults</a></p> <p><b>Paulette goes for an eye test</b> An animation by Leeds Animation Workshop <a href="http://www.easyhealth.org.uk/content/paulette-goes-eye-test">www.easyhealth.org.uk/content/paulette-goes-eye-test</a></p> <p><b>A visit to the optician</b> A film by Easyhealth <a href="http://www.easyhealth.org.uk/content/visit-optician">www.easyhealth.org.uk/content/visit-optician</a></p> <p><b>Going to the opticians</b> A photo journey by Rotherham, Doncaster and South Humber NHS Foundation Trust <a href="http://www.improvinghealthandlives.org.uk/adjustments/?adjustment=243">www.improvinghealthandlives.org.uk/adjustments/?adjustment=243</a></p> <p><b>Choosing an optometrist</b> Use SeeAbility's optometrist database to find a local optometrist and to see what Reasonable Adjustments they can make for people with learning disabilities <a href="http://www.seeability.org/eyecare_hub/optometrists_in_your_area/optometrist_search.aspx">www.seeability.org/eyecare_hub/optometrists_in_your_area/optometrist_search.aspx</a></p> <p><b>Functional Vision Assessment</b> Use SeeAbility's Functional Vision Assessment tool to find out more about how much someone can see. The tool helps you to identify new sight problems or to monitor existing visual difficulties: <a href="http://www.seeability.org/eyecare_hub/carersandsupportersinfo/eye_problems/functional_vision_assessment_fva.aspx">www.seeability.org/eyecare_hub/carersandsupportersinfo/eye_problems/functional_vision_assessment_fva.aspx</a></p>
After the eye test	<p><b>Feedback from the optometrist about my eye test</b> An Easy Read form to help someone understand the results of their eye test <a href="http://www.seeability.org/myeyecare/eye_test/feedback_from_optom.aspx">www.seeability.org/myeyecare/eye_test/feedback_from_optom.aspx</a></p>

The following examples demonstrate how reasonable adjustments are being put into place locally.

### Supporting people to get eye checks in Plymouth

In Plymouth, people with learning disabilities are encouraged to fill out the SeeAbility pre appointment sheet “Telling the optometrist about me”

[www.seeability.org/myeyecare/eye\\_test/telling\\_optom.aspx](http://www.seeability.org/myeyecare/eye_test/telling_optom.aspx) and take it to the optometrist.

Having a regular eye check is also written into the Health Action Plan. One local optician is particularly good at making reasonable adjustments to meet people’s needs. If required he will see people at a time to suit them, and will allow them plenty of time. He will also visit people in their own homes. SeeAbility are arranging a training session in Plymouth on the importance of having your eyes checked on a regular basis. The SeeAbility DVD is also going to be used in regular health promotion education events.

For further information please contact [Kath.ingram@nhs.net](mailto:Kath.ingram@nhs.net)

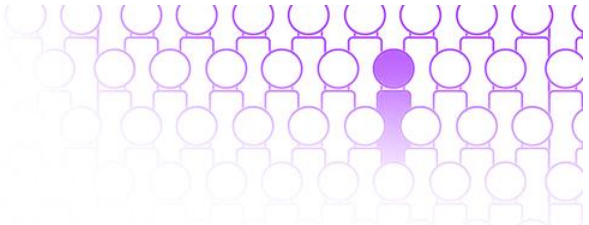
### Supporting people to get eye checks in Bexley

Bexley PCT has put in place a Local Enhanced Service (LES) for those patients registered with a Bexley GP who have a moderate/severe learning disability and have a Personal Health Profile (PHP) with Oxleas Foundation Trust. A LES is a scheme agreed by PCTs in response to local needs and priorities, sometimes adopting national service specifications. The aim of the LES is to:

- ensure people with learning disabilities have timely and appropriate access to eye care locally, including access to further treatment;
- reduce the risk of diagnostic overshadowing (assuming the issue is to do with the person’s learning disability, and thus failing to diagnose the condition);
- improve the information available to those caring for individuals with complex needs enabling development of appropriate care plans;
- improve communication between optometry and other health and social care providers;
- ensure adequate information for GPs to complete reports and annual health checks for people with learning disabilities;
- reduce health inequalities for this group.

Eligible patients are given a pack containing the SeeAbility pre examination questionnaire “Telling the optometrist about me” and list of accredited optometrists. Paperwork is also held by accredited optometrists, and GPs can refer patients for examination. Once the patient has seen the optometrist of their choice, a copy of the patient record is sent to their GP, and information is added to the PHP.

The Local Optical Committee Support Unit (LOCSU) has developed a nationally agreed pathway modelled on the Bexley pathway among others, and agreed by stakeholders such as SeeAbility, Mencap and the Department of Health. The pathway can be used by any local PCT/CCG or other commissioning organisation in conjunction with their Local Optical Committee to develop a service in their area. For further information please contact: [info@locsu.co.uk](mailto:info@locsu.co.uk)



### **Supporting people to get eye checks in Tower Hamlets**

Tower Hamlets established a vision clinic as part of a partnership project with the Community Learning Disability Service, the Royal London Hospital Ophthalmology service and SeeAbility. Three opticians in Tower Hamlets have also been trained regarding reasonable adjustments to eye tests. The partnership ran an Eye Health Champions Day and trained a number of people with learning disabilities to be eye champions. Following the training, eye champions made posters to help other people with learning disabilities know where to get help about eye care.

For further information, please contact: [Jean.Charalambous@bartshealth.nhs.uk](mailto:Jean.Charalambous@bartshealth.nhs.uk)

### **Bridge to Vision project - Leeds**

Leeds have trained eight Vision Champions as well as running a three day basic awareness course for 50 staff from health and social care as part of the Bridge to Vision project. The Vision Champions talked about their role and the project at a city wide Optometrist workshop regarding supporting people with learning disabilities in October 2012. 26 Optometrists attended. They have also delivered awareness raising sessions regarding Bridge to Vision and the role of Vision Champions to team meetings across learning disability health and social care, and have displayed posters about the project in a variety of settings, which include contact details of Vision Champions. Some teams have “supporting service users to access eye care” as part of their staff objectives for 2012/13.

Following training, one of the Vision Champions noticed that a woman with learning disabilities had symptoms of keratoconus. Her eyes were a curved shape, she held her magazine close to her face when reading, and squinted when she looked at people, behaviours that were likely to be compensating for poor vision. An appointment was made for the woman at the local optician, and a pre-appointment form was completed to help inform the optometrist how best to communicate with her. The woman did have keratoconus, and was referred to the hospital for further assessment and treatment. Information on her visual needs and eye health has now been integrated into care plans. The Vision Champion used the opportunity to educate the nursing team on what to look out for in other people with learning disabilities.

For more information please contact: [Norman.Campbell@nhsleeds.nhs.uk](mailto:Norman.Campbell@nhsleeds.nhs.uk)

### **Supporting people to get better eye care services in Bradford**

Bradford District Care Trust and Bradford Teaching Hospitals have developed a patient pathway which links existing community and hospital services to enable identification and treatment of people with learning disabilities and eye problems. The community team ensure vision is discussed as part of regular health reviews and the importance of eye checks is communicated to the carers. A specialist orthoptist screens patients with moderate and severe learning disability annually, and will take referrals about any patient for whom there is a concern about vision. An assessment of functional vision is undertaken at a community health centre or at their residential home to ensure patients are at their most relaxed in a familiar environment. Patients for whom there are concerns about vision are referred directly to a member of the consultant ophthalmology team in the hospital.

The learning disability support staff in the community provide information direct to the ophthalmologist about the patient's medical background and likely ability to tolerate various tests in the clinic, which also doubles as a way of preparing the patient and carer for what might happen in clinic. Appointments are arranged at a time which suits the patient and carer and are directly relayed to the community team who can then ensure appropriate support is available in clinic and liaise to arrange desensitisation visits if required. On arrival, patients are identified at the front desk, and seen with minimum wait in a quiet area, and repetition of testing or inappropriate visual acuity testing is avoided. Reasonable adjustments, such as multiple appointments to complete the examination, are commonly used. Outcomes of the appointment are communicated directly to the patient, carer and community team.

For further information please contact: Rachel Pilling [rachel.pilling@bthft.nhs.uk](mailto:rachel.pilling@bthft.nhs.uk)

### **Supporting people to get eye checks in Kent**

SeeAbility forms and information are used by Kent Community Health Trust's Sensory Department to support people to positively access eye care services. Team members work with individuals to familiarise them with ophthalmic procedures. Please see:

[www.improvinghealthandlives.org.uk/adjustments/?adjustment=244](http://www.improvinghealthandlives.org.uk/adjustments/?adjustment=244) . They will accompany individuals to eye checks when necessary, and take notes so that they can explain any issues to the individual, support staff and family. They will also produce tailor-made accessible information. The Head of the Sensory Department is a general and ophthalmic trained nurse and has worked in an Ophthalmic Hospital, therefore is familiar with the 'jargon' and able to 'challenge' as required and appropriate at these appointments.

For further information please contact: [Brenda.Fox@kent.gov.uk](mailto:Brenda.Fox@kent.gov.uk)

## Supporting people to get better eye care services in Torbay

About five years ago, a pilot study was carried out in Torbay to investigate whether people with learning disabilities were accessing the eye care they needed. For further information please see the pilot study report: [www.improvinghealthandlives.org.uk/adjustments/?adjustment=246](http://www.improvinghealthandlives.org.uk/adjustments/?adjustment=246) . The study confirmed the importance of an orthoptist with an extended role to coordinate local services to improve access to eye care for people with learning disabilities in South Devon. The role incorporates three main areas:

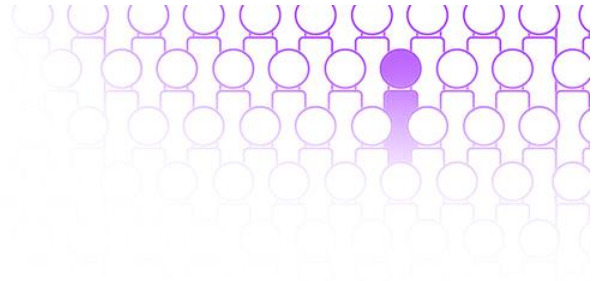
**Raising awareness** -people with learning disabilities are encouraged to access primary care and visit their local optometrist wherever possible. A leaflet using Total Communication techniques entitled "Getting my Eyes Checked" was produced: [www.improvinghealthandlives.org.uk/adjustments/?adjustment=247](http://www.improvinghealthandlives.org.uk/adjustments/?adjustment=247) and is distributed widely within the local area including learning disability teams, GP surgeries and at health promotion events. The orthoptist visits further education departments in all local special schools to talk to young people (at the point of transition from child to adult services) about what happens when they have an eye test and gives them a copy of the leaflet. She also has close working links with the local community primary care liaison nurses and has jointly produced a flow chart for local GP's to aid with the vision section of the annual health check: [www.improvinghealthandlives.org.uk/adjustments/?adjustment=248](http://www.improvinghealthandlives.org.uk/adjustments/?adjustment=248) . The orthoptist and the Speech and Language Therapist sit on the Hospital Learning Disability Steering Group to help develop smooth links between the hospital and community eye care pathway.

**Desensitisation** - most people with learning disabilities were not accessing eye appointments because they or their carers felt they would be unable to co-operate with eye tests. Linking with the community learning disability teams has enabled the provision of specific tailored desensitisation for people needing eye appointments, especially for those who need assessments at the hospital eye clinic. Learning disability champions in the eye clinic can work with the teams to ensure that sessions are relevant to each individual.

**Home visits**- the pilot study identified a small group (approx. 13%) of people with severe learning disabilities where accessing primary services was not appropriate. The orthoptist is now able to offer these people a home eye check. Carers can be provided with practical advice about a person's functional vision and it is possible to arrange follow up appointments with the consultants at the hospital eye clinic or their local optometrist. Reasonable adjustments ensure that a double appointment slot can be arranged at a convenient time, preferably at the end or beginning of a clinic when it is less busy, and by doing a home eye check in advance it provides the consultant with information prior to the consultation and also reduces the time needed on the day of the appointment.

For further information please contact: [Kathy.diplock@nhs.net](mailto:Kathy.diplock@nhs.net)





### **Supporting people to get eye checks in Kensington and Chelsea**

In the Royal Borough of Kensington and Chelsea, the Optometry Advisor has asked all the ophthalmic contractors and trainee optometrists in all three boroughs to use the SeeAbility's pre-assessment form "Telling the optometrist about me" to gather information about patients with learning disabilities before they are seen, allowing for appropriate reasonable adjustments to be made so that the appointment goes ahead successfully. Using reasonable adjustments, the advisor also ran eye check sessions for several patients, some of whom have complex needs. Patients who had not been to see an optometrist for years said they now felt they will be happy to visit more frequently. The specialist learning disability team are working on how ophthalmic practices in the community can provide adequate eye care for patients with complex needs.

For further information please contact: [Rifat.Wahhab@rbkc.gov.uk](mailto:Rifat.Wahhab@rbkc.gov.uk)

## Having treatment

At the hospital	<p><b>Eye surgery support plan</b> Use this Easy Read tool to support someone to have an eye operation <a href="http://www.seeability.org/myeyecare/eye_operations/eye_surgery.aspx">www.seeability.org/myeyecare/eye_operations/eye_surgery.aspx</a></p> <p><b>Eye conditions</b> Easy Read information about eye conditions <a href="http://www.seeability.org/myeyecare/eye_conditions/">www.seeability.org/myeyecare/eye_conditions/</a></p> <p><b>Eye operations</b> Easy Read information about eye operations <a href="http://www.seeability.org/myeyecare/eye_operations/">www.seeability.org/myeyecare/eye_operations/</a></p>
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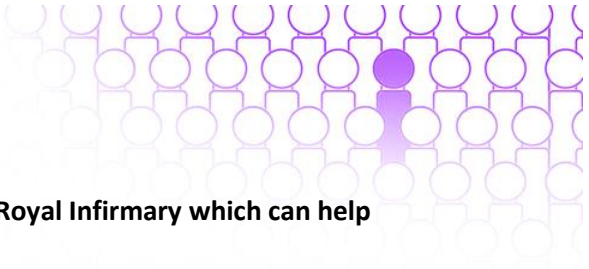
### Eye surgery and day surgery reasonable adjustments - Torbay hospital

Torbay eye surgery unit runs desensitisation sessions to help people with learning disabilities get used to the environment, improve their experience of clinic appointments, and enable better clinical outcomes. Clinic appointments can be arranged in a quiet area which is less stressful. Desensitisation includes letting patients take wristbands home so they can get used to wearing them in their own environment, and the unit is going to trial using a basic cream like Savlon and some clear patches to emulate the numbing cream Emla, so patients can get used to the procedure. The eye surgery unit has designed a form to record what has been achieved in the desensitisation sessions, and information on what the patient can and can't tolerate, which helps the doctor when it comes to the examination. A copy of the form can be found at:

[www.improvinghealthandlives.org.uk/adjustments/?adjustment=245](http://www.improvinghealthandlives.org.uk/adjustments/?adjustment=245)

A picture book has been developed for day surgery showing a woman going through the whole process ( both in hospital gown and day clothes as not all procedures require removal of day clothes), which includes the person arriving and waving goodbye, as this seems to reassure people. A version is being developed for men. The acute liaison nurse tries to introduce the patient to the named nurse prior to the admission date so they know who to expect and will be with those that request it. Parents and carers are encouraged to come to theatre to reassure the patient and cannulas are removed before returning to the side room if possible, if the cannula causes the patient distress.

For further information please contact: [roz.erskine-gray@nhs.net](mailto:roz.erskine-gray@nhs.net)



**Below is a list of possible Reasonable Adjustments from Bradford Royal Infirmary which can help someone to access good hospital eye clinic care.**

For further information, please contact: [Rachel.Pilling@bthft.nhs.uk](mailto:Rachel.Pilling@bthft.nhs.uk)

#### **Making the appointment**

- To have a nominated lead for learning disabilities such as sister/charge nurse in charge of eye clinic. This person may pick up new referrals for people with learning disabilities.
- Administration staff aware that changes can be made
- Adjustments to consider
  - Early appointment
  - Particular time of day
  - Kept waiting as little as possible
  - Visit to the department prior to appointment
  - Split visits to reduce time in eye clinic
  - No eye drops or do eye drops at home first

#### **Patient information**

- Carer providing information about patient medical condition
- Carer providing information about patient's visual performance
- What might the patient find difficult about the examination?
- How does the patient feel about being touched?
- Hospital providing information on what sort of tests might be included in visit to clinic so patient can be prepared

#### **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

#### **How might the person have their vision checked?**

- Matching shapes
- Orthoptist to do vision check
- Functional assessment - Why is there concern about vision?
- What has changed for the person?
- What activities does the patient now find difficult?

### 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
- Utilise SeeAbility's optometrist feedback form
- Provide information leaflet/easy read information
- Consider another appointment to come back and ask more questions

### General

- Communicating with the patient where possible
- Considering more than one appointment to complete eye test
- People with learning disability are "vulnerable patients" and should be exempt from Did Not Attend (DNA) policies

### Glasses

- "Feeding" glasses are as important as "reading" glasses – patients who cannot read should not be denied glasses to help them see close up
- Glasses should be discretely labelled – with the patient's name if they live in a shared setting – and with their purpose (near or distance) if they have more than one pair

### Theatre

- Patient and carer can visit day case unit/ward before day of operation to familiarise themselves with the ward
- Pre operative checks can be done under anaesthesia if necessary
- Consent should not be a barrier to surgery – involve carer, next of kin and best interest meeting if necessary. This process should not be rushed in order to fulfil trust waiting time targets
- Theatre list should be ordered to minimise patient wait (first on list where possible)
- Timing of operation (morning or afternoon) should be discussed with patient and carer. Being in hospital by 7.30 for a morning list may be difficult; being kept starved all morning for an afternoon list may be a challenge: consider allowing patient to arrive outside normal theatre arrival times
- Carer should be allowed to be present in recovery where possible. Avoid overnight stay if possible

## Service evaluation

Questionnaire	<b>Feedback on eye care</b> Questionnaire asking for feedback on eye care services in Calderdale <a href="http://www.improvinghealthandlives.org.uk/adjustments/index.php?adjustment=124">www.improvinghealthandlives.org.uk/adjustments/index.php?adjustment=124</a>
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## Conclusion

People with learning disabilities are more likely to have visual impairments than their non-disabled peers. Therefore it is important for public sector organisations to put reasonable adjustments in place so that people with learning disabilities can access eye care services effectively. This report signposts professionals, support workers and family carers to numerous resources that can be used to enable people with learning disabilities to access eye care services. A number of examples of how these resources are being used have been included.

## Glossary of eye care professionals

### **Optometrist**

Optometrists are qualified to carry out eye examinations, advise on eye care and recognise abnormal conditions. They prescribe and fit spectacles, contact lenses and low vision appliances (such as magnifying aids). They work in private practices in high streets, hospital eye departments or health centres/community clinics.

### **Optician**

Opticians (dispensing opticians) are qualified to fit and adjust spectacles. Some are further qualified to fit contact lenses or low vision appliances from a prescription supplied by an ophthalmologist or optometrist. They work in high street premises or hospital eye departments.

### **Ophthalmologist**


Ophthalmologists/ophthalmic surgeons are medically qualified doctors who are concerned with medical and surgical conditions of the eye and their treatment. They work in hospital eye departments, health centres/community clinics or in private practice.

### **Orthoptist**

Orthoptists are qualified to diagnose and treat problems related to binocular vision such as squints and double vision. They work closely with ophthalmologists and other members of the 'eye care team'. They work mostly with children and people who have had a stroke or head injury.

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