

**Delivering an equal right to sight**

**A report by SeeAbility (2016)**

**Large print 16 pt version**

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## **Foreword by Lord Holmes of Richmond MBE**

People with learning disabilities are ten times more likely to experience serious sight problems than the general population, a disparity that is even more marked at a young age, so it is vital that their eye care needs are recognised and accommodated.

This report looks at new information, research, good practice, and most importantly gives a voice to people with learning disabilities on what is important to them when they go for a sight test and receive eye care.

Everyone deserves an equal right to sight. SeeAbility and many others have undertaken much excellent work in this respect. I would urge readers to make use of SeeAbility's free resources, expertise and support.

However, we are over twenty years on from the Disability Discrimination Act and this report shows that we are not at the stage where everyone, regardless of disability, is accessing their right to good eye care. This is robbing people of independence and quality of life.

The report makes a number of recommendations. Sight tests are low cost, preventative tools that every health economy should embrace. Hospitals should be the last resort for people with learning disabilities who just need routine eye care, and community alternatives need to be nationally available. For example, many children attending special schools could benefit hugely from a programme that brings sight tests and glasses into their school. Working age adults with learning disabilities

could benefit from free NHS sight tests just as other high risk groups do.

It has been said if we can get eye care right for people with learning disabilities, we can get it right for everyone. I hope that this report gives inspiration and information in equal measure, and provides the impetus for much needed change in the eye care system, putting us all on the road to delivering an equal right to sight.

Lord Holmes of Richmond MBE

## Summary

Delivering an equal right to sight looks at new information, research, good practice and most importantly gives a voice to people with learning disabilities about what is important to them when they go for a sight test and receive eye care. It finds:

### **1. People with learning disabilities of all ages experience alarmingly high levels of sight problems.**

In 2016 we estimate numbers are at their highest level yet, with hundreds of thousands of adults and children with learning disabilities experiencing poor vision.

- 1 in 10 of the learning disability population of England will be blind or partially sighted.
- Adults with learning disabilities are 10 times more likely to have a serious sight problem than other people. 6 in 10 people with learning disabilities will need glasses.
- Children with learning disabilities are 28 times more likely to have a serious sight problem than other children.

The more profound and complex a person's learning disability is, the more likely they will have a serious sight problem and certain conditions, such as Down's Syndrome, are known to cause issues with eyesight. Older people with learning disabilities may also experience age-related threats to eyesight. People with learning disabilities experience higher rates of diabetes, and with this can come with complications including sight problems.

## **2. Many people with learning disabilities are missing out on eye care and some are tragically losing their sight because of this.**

In a recent study 50% of adults with learning disabilities had not had a sight test in the recommended period. 4 in 10 of children in special schools have never had a sight test.

Sight tests don't just help people get the glasses they need to see clearly but can identify serious sight threatening issues like cataracts and glaucoma that can then be treated. Unfortunately there is also evidence that people are missing out on these important eye treatments and surgery.

Anyone with a learning disability who isn't being given the chance to see clearly or has suffered totally avoidable sight loss is being robbed of independence and quality of life. The person might be at more risk of depression, anxiety, trips or falls, accidents, even challenging behaviour, and more reliant on high cost care and support.

## **3. People with learning disabilities need extra support and help to get the eye care they need: no one is 'too disabled' to have a sight test.**

It is really important that people with learning disabilities and their supporters are aware that sight tests are important checks to have, and that you don't have to be able to speak or read to have your sight checked.

If someone has more profound disabilities and cannot speak they may not be able to recognise or communicate that they have a sight problem. This means those supporting people with

learning disabilities need to be aware of tell-tale signs of possible problems with vision and make sure people are supported to get a sight test, and to wear and look after their glasses, if they are needed.

Eye care settings should be aware of their duty to provide reasonable adjustments and provide information in an accessible format. Community optical practices and hospital eye clinics should proactively identify if someone has a learning disability, and have good policies and procedures in place, including making use of easy read information and awareness training.

Often all people with learning disabilities need is time, understanding, and having things explained to them in an accessible way. Sadly there are still cases where people have not had a good experience.

#### **4. There are projects across the country supporting people with learning disabilities that others can learn from.**

There are people with learning disabilities who are getting excellent eye care from professionals, and there are initiatives and projects especially targeting people with learning disabilities which are shared in the full report. These include projects set up and driven by people with learning disabilities and SeeAbility.

**In Barking and Dagenham**, local commissioners have put in place a LOCSU pathway for eye care so people with learning disabilities can use accredited optometrists, who offer longer appointments and resources to support the person to have a

sight test. Similar work is happening in Bexley, Sutton, Greater Manchester and Durham.

**In Bradford**, the Learning Disability Eye Service team based at the NHS Trust has won awards for supporting people with learning disabilities including supporting access to eye surgery. Bradford People First self-advocacy group is providing training for people with learning disabilities on eye care and vision.

**In Ealing**, not for profit organisation Certitude's 'Treat me Right' health campaign has been working with services and support staff to assist people to look after their eyes and vision, through taking part in SeeAbility's 'Eye Care and Vision Charter.'

**In Torbay Hospital, Devon**, the lead orthoptist is working to break down barriers and co-ordinate access to eye care for adults with learning disabilities, from helping people have their eyes checked at home or in residential care, to ensuring that reasonable adjustments are made in the clinical setting, for example in diabetic eye screening.

**In Worcestershire**, people with learning disabilities from the Speakeasy N.O.W group have run their own review of how health services are making reasonable adjustments, visiting local optometrists and hospital eye clinics.

## **5. NHS England's national funding system for sight tests is letting down people with learning disabilities**

Working age adults with learning disabilities are not automatically entitled to NHS funded sight tests. They can be faced with a confusing means test and may have to pay for their sight test as well as their glasses, unlike people in other

high risk groups who are entitled to a NHS funded sight test – such as those with a family history of glaucoma.

NHS England operates a national budget and contract for NHS funded sight tests and help towards the cost of glasses, the General Ophthalmic Services or ‘GOS’ contract, but this has remained largely unchanged for many years, including a fee of circa £20 paid to optometrists for a sight test. The fee structure does not take account of the fact that those with learning disabilities may need longer or multiple appointments in community optical practices or other settings, such as special schools. At the time of writing, there are five areas of the country where local health commissioners are trying to fill the gap with dedicated pathways of community eye care.

People with learning disabilities often say that they are put off by the possible costs of both sight tests and glasses. This can leave people using their GP or visiting hospital with eye problems – services that are under tremendous pressure.

It is concerning that data on how many people with learning disabilities are getting sight tests or eye care is so poor, while NHS and government strategies to improve the lives and health of people with learning disabilities say very little about improving the current system, despite good vision being so key to independent living.

## **6. Recommendations for reform**

Specific actions need to be taken to support people with learning disabilities to get the eye care they need, so they do not have to worry about cost or where to go:

- i. **Working age adults with learning disabilities should be eligible for NHS funded sight tests**, just as other high risk groups are.
- ii. **NHS England should introduce a national learning disabilities eye care pathway funded through national enhancements to the GOS scheme**, so accredited community optical practices can offer longer or split appointments and people with learning disabilities know where they can go and get onward referral and treatment if needed.
- iii. **With only just over 100,000 pupils there should be a national programme for properly funded sight tests and glasses dispensing in special schools**. This would enable children with some of the most profound needs to access their right to a free NHS sight test.
- iv. **There should be a review of how people can better access spare glasses and more resilient frames to meet their needs**. And people with learning disabilities will often need particular frames, fitting and support with their glasses – we recommend this should be by dispensing opticians or optometrists rather than unregistered staff.
- v. **NHS England must address the void in patient data, including access to eye care by people with learning disabilities** and what outcomes they experience.
- vi. **There should be better training and recognition of the visual needs of people with learning disabilities across health and social care**, particularly for

professionals such as GPs and care staff who are the 'gatekeepers' for health checks and treatment.

- vii. **Eye care should be embedded in national learning disability policy and programmes**, including the Transforming Care Programme and the GP annual health check scheme. This is especially important given there is no parallel national NHS strategy for eye care.
- viii. **A national awareness campaign is needed to reiterate these messages** on the high risk of vision problems in people with learning disabilities, on the benefits of sight tests, that no one is 'too disabled' to have a sight test and provide advice on routes to challenge discriminatory practice.

## **About SeeAbility and this report**

SeeAbility is a UK charity supporting people with sight loss and multiple disabilities. As well as providing specialist support, housing and social care, we have expanded our work in recent years to raise awareness of the high risk of sight problems in people with learning disabilities. We have a wealth of information including easy read factsheets about eye care and eye health and an easy to use database of optometrists who can support people with learning disabilities to have an eye test and access good eye care. We also offer training in eye care and vision.

## **Acknowledgements**

The many people who took part in our surveys, and the charities and groups which were so supportive in helping us to promote our surveys to gather data for this report.

The people who use SeeAbility services and their families, and the many individuals, professionals and professional bodies who have worked with SeeAbility to improve eye care and have shared their good practice and experiences in this report.

## **Report coverage**

- **UK situation**

This report concentrates on the situation in England but many of the key messages and resources will be of interest to the rest of the UK. The need to act according to equalities law and ensure people receive healthcare that is reasonably adjusted is UK wide, however the system of eye care is different in each country in terms of policy, commissioning, funding and training.

- **Learning disability and autism**

In this report we use the term 'learning disability'. A learning disability has been defined as 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 can be affected very differently, from being able to live very independent lives to perhaps needing more full time care and support, particularly if they have other physical disabilities (source, Mencap).

Learning disability should not be confused with autism, which is a lifelong development disability that affects people in different ways. Difficulties may be expressed with communication, social imagination or social interaction. However some people with autism may also have a learning disability and it can be associated (source, National Autistic Society).

# **Part 1: Introduction and context**

## **Scott's story**

Scott Watkin is SeeAbility's Eye Care and Vision Development Officer. Scott, who is 34, has an eye condition called keratoconus. This is one of the eye conditions that people with learning disabilities are at more risk of having and can make vision blurry and distorted, getting worse over time.

When Scott was young a nurse at his special school spotted a problem with his eyes. Scott says:

"My eye care journey started nearly 30 years ago. I have memories of going to the optician, and then to the hospital, with its busy waiting room to have my eye test.

When I was older I was told that I should stop studying gardening at college, as getting soil and dirt in my eyes was not advisable. It was heartbreaking to give this up. I was also given hard contact lenses to flatten the cornea so I could see better. I showed challenging behaviour as I could not stand them, they grazed my eyes and sometimes fell out. They can cause serious damage to your eyes if you don't put them in properly.

My sight was getting worse. I could only see a metre or so in front of me. I was unemployed because I couldn't really see. It was a bad time for me.

I knew surgery, called a 'corneal graft' would help. But it wasn't easy to get this. People assume that people with learning disabilities won't cope or won't see the benefit. But my mum and I made sure it went ahead. Afterwards I needed lots of help with eye drops and sometimes care staff didn't know how to do this.

When I recovered my world opened up and I got a job, starting on my career to speak out for people with learning disabilities. I also got news about my second corneal graft. This time I got the right support to recover after surgery.

During this time I knew I wanted to help other people with learning disabilities get good eye care. That is what I am doing in my job with SeeAbility. I travel around the country in my work and also do a lot of work with government. I also have a young family to support.

But I sometimes wonder what I might be doing if I hadn't had my eye surgery.

It makes me sad that other people with learning disabilities might have their eyesight neglected. It shouldn't be down to luck that someone spots you have a problem with your eyes. Just because someone has a learning disability doesn't mean their sight isn't as important as anyone else's or barriers should be put in their way."

## **The high risk of sight problems in people with learning disabilities**

### **Key message**

**People with learning disabilities are many times more likely to have serious sight problems. In 2016 numbers are at their highest level yet, with hundreds of thousands of people with learning disabilities experiencing poor vision. 1 in 10 of the learning disability population of England will be blind or partially sighted. 6 in 10 people with learning disabilities will simply be in need of a pair glasses.**

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Sight loss affects about two million people in the UK and it has been estimated that around 50% of sight loss is preventable. The most common cause of visual impairment is uncorrected refractive error (short or longsightedness, or astigmatism), along with age-related macular degeneration, cataract, diabetic retinopathy and glaucoma.<sup>1</sup>

As the population ages and underlying causes of sight loss increase (for example, diabetes) so sight loss is expected to grow. And more early on in life, concern has been expressed about the growing numbers of shortsighted children.<sup>2</sup>

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<sup>1</sup> RNIB (2014). Sight loss: A public health priority.

<sup>2</sup> Findings from the Northern Ireland Childhood Errors of Refraction Study (NICER) by the University of Ulster. See College of Optometrists: [www.college-optometrists.org/en/college/news/index.cfm/NICER\\_Myopia\\_Children](http://www.college-optometrists.org/en/college/news/index.cfm/NICER_Myopia_Children).

However, perhaps less well known is that people with learning disabilities **of all ages** are at a greatly increased risk of sight problems.<sup>3</sup>

When we surveyed young people and adults with learning disabilities for this report, **6 in 10** said they had problems with their vision.

There is no national data collection on the number of people with learning disabilities who also have problems with their vision. While there are registers of blind and partially sighted people held by local authorities in England, these are voluntary and not a definitive measure of all people who have sight problems. Back in 2011 SeeAbility and the RNIB funded research to estimate numbers of people with learning disabilities and sight problems in the UK as well as each country within the UK. The report also looked forward five years on to 2016.

**In 2016, the number of people with learning disabilities and sight problems in England is estimated to be at their highest level yet:**

- An estimated 85,161 adults and 19,748 children with learning disabilities are blind or partially sighted. This is about **1 in 10** of the learning disability population of England.

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<sup>3</sup> For example, see: Warburg M. (2001) Visual impairment in adult people with intellectual disability: literature review. J Intellect Disabil Res 45:424-38. This paper reviewed studies on prevalence in adults and stated “every publication describes an alarming prevalence of visual impairment and blindness.”

- Adults with a learning disability are **10 times more likely** to have a serious sight problem than other adults.
- 504,796 adults with a learning disability have refractive error. This means around **6 out of 10 people** with learning disabilities in England need glasses.
- Children with learning disabilities are **28 times more likely** to have a serious sight problem than other children.

### Further reading

Emerson and Robertson (2011) The Estimated Prevalence of Visual Impairment among People with Learning Disability in the UK. The tables in this publication also give individual breakdowns for each country in the UK as well as England. [www.seeability.org/uploads/files/PDFs\\_Books\\_non\\_Easy\\_Read/PWLD\\_VI\\_prevalence\\_report.pdf](http://www.seeability.org/uploads/files/PDFs_Books_non_Easy_Read/PWLD_VI_prevalence_report.pdf)

UK Vision Strategy (2014). Eye Health Data Summary, a review of published data in England. [www.ukvisionstrategy.org.uk/get-involved-ways-get-involved-across-uk-england/eye-health-data-summary-england](http://www.ukvisionstrategy.org.uk/get-involved-ways-get-involved-across-uk-england/eye-health-data-summary-england)

## **Common sight problems amongst people with learning disabilities**

### **Key message**

**People with learning disabilities associated with particular conditions, such as Down's Syndrome, or those with more profound and complex needs are at greater risk of having sight problems. Older people with learning disabilities will also be at greater risk of age-related threats to eyesight. People with learning disabilities who have diabetes will also need their eyesight monitoring.**

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The sight problems that people with learning disabilities experience can range from high refractive errors, squint/eye turn, poorly controlled or involuntary eye movements, developmental abnormalities of the eye, damage to the optic nerve to problems with how the brain processes vision (commonly termed cerebral visual impairment).

There may be more of a risk of developing cataracts at an early age (where the lens in the eye clouds) or keratoconus (where the shape of the eye's outermost layer changes). Around 4% of people with learning disabilities may self injure and this can risk damage to eyesight or, in rare cases, cause blindness.

Certain conditions such as Down's Syndrome and Cerebral Palsy can also increase risk of sight problems<sup>4</sup> and there is

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<sup>4</sup> For example, see Krinsky-McHale et al. (2012). Ophthalmic Disorders in Adults with Down's Syndrome. Current Gerontology and Geriatrics Research Vol. 2012.

increasing evidence that autism is associated with poorer sight. Juvenile Batten Disease first presents in children and young people through degenerating sight.

Visual impairment is also greater amongst people with more profound and complex learning disabilities, which has led researchers to suggest that all persons with severe or profound learning disabilities, and all older adults with Down's Syndrome, should be considered visually impaired until proven otherwise.<sup>5</sup> This means vision problems are high in settings more likely to support people with profound needs.<sup>6</sup> For example in one study of over 500 people being discharged from a large institution to their community a staggering 99% of those able to have a sight test had a problem with their vision.<sup>7</sup>

In special schools, where SeeAbility has been providing sight tests, we have found over half of children have a problem with their vision.<sup>8</sup>

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<sup>5</sup> Van Splunder et al. (2006). Prevalence of visual impairment in adults with intellectual disabilities in the Netherlands: cross sectional study. *Eye* (2006) 20, 1004 -1010.

<sup>6</sup> Van Isterdael et al (2006). 6220 institutionalised people with intellectual disability referred for visual assessment between 1993 and 2003 overview and trends. *Br J Ophthalmology* (2006) 90 (10) 1297 – 1303.

<sup>7</sup> Kerr, A et al. (2003). Medical needs of people with intellectual disability require regular reassessment and the provision of client and carer held reports. *Journal of Intellectual Disability Research*. Volume 47 Issue 2 pp.134 -135

<sup>8</sup> SeeAbility (2016). 28 times more likely. *The Children in Focus Campaign second annual report*.

People with learning disabilities also experience greater rates of diabetes<sup>9</sup> and with this comes the increased risk of developing the sight conditions of diabetic retinopathy or glaucoma. Older people with learning disabilities will be at additional risk of age-related sight conditions too, such as refractive error due to ageing, age-related macular degeneration or cataracts.

### **Further reading**

For more information on common eye conditions amongst people with learning disabilities see SeeAbility's website [www.seeability.org/sharing-knowledge](http://www.seeability.org/sharing-knowledge)

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<sup>9</sup> Improving Health and Lives. Learning Disabilities Health and Care Project findings (2016).

## **Case study: Raising awareness of vision issues for people with Down's Syndrome**

Kate Powell blogs for the Down's Syndrome Association and every year the charity has a 'vision month' with lots of information and advice on looking after your eyesight.

Even with glasses someone with Down's Syndrome may not have good vision in terms of being able to view things clearly (poor visual acuity).

Kate says:

“Keep wearing your glasses so you can see more clearly, keep going for your eye tests to keep your eyes healthy.”

Children with Down's Syndrome often struggle to find properly fitting glass frames which means they can't see well, despite having the right lens prescription. The Down's Syndrome Association is campaigning to find a solution to this problem and is currently supporting research being carried out with Alicia Thompson of the Association of British Dispensing Opticians (ABDO). More information on Alicia's work is in Part 3 of this report.

See [www.downs-syndrome.org.uk](http://www.downs-syndrome.org.uk)

## **Current policy to improve the health of people with learning disabilities and prevent sight loss**

### **Key message**

**People with learning disabilities still experience health inequalities and disability discrimination despite protection under the law. There is an aim for more people to get early eye care, and there is a national indicator to measure reasons for sight loss. However there is no NHS strategy for eye care in England and very little is being said about eye care in new government and NHS strategies for people with learning disabilities.**

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Anyone with a disability should find themselves protected by anti-discrimination and equalities legislation. The entitlement to have a national health service that meets needs through ‘reasonable adjustments’ and through reducing inequalities is crucial.<sup>10</sup>

Despite this people with learning disabilities still have poorer health and a shorter life expectancy than the general population. A number of campaigns and formal inquiries have reported on these issues.<sup>11</sup> A learning disabilities public health observatory ‘Improving Health and Lives’ was created in 2010, to understand better what was happening, and to gather data and good practice from across England.

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<sup>10</sup> For example, see the Health and Social Care Act 2012.

<sup>11</sup> For example, Mencap (1998) Death by Indifference, and the Disability Rights Commission (2006) Equal Treatment – Closing the gap.

It is also national policy to prevent sight loss. As part of a public health framework<sup>12</sup>, the rates of certified sight loss in each local authority are being measured each year and give an indication of reasons why people are losing their sight.

This is helping organisations like Vision 2020 UK, part of a global initiative to eliminate avoidable blindness, and the England Vision Strategy, a cross sector strategy to prevent sight loss and support people with sight loss. The Strategy has a particular aim of ‘detecting eye conditions early, especially in seldom heard groups’. Unfortunately though there is no NHS England strategy for eye care.

Most recently, the government and the NHS<sup>13</sup> have set out an aim to transform care for people with learning disabilities including their healthcare. This includes discharging people from assessment and treatment units under the ‘Transforming Care Programme’. However these current plans and strategies for people with learning disabilities say very little about the high risk of vision problems that people with learning disabilities experience, or specifically ensuring people have sight tests and improved access to eye care.

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<sup>12</sup> Public Health England (2016). Public Health Outcomes Framework.

<sup>13</sup> NHS England (2015). Building the NHS of the Five Year Forward View. The NHS England Business Plan 2015/16.

## The impact of sight loss

Sight loss affects different people in many different ways.<sup>14</sup> The issues range from the financial impact, the lack of emotional support on offer, to feeling cut off from society, loss of employment opportunities, to being unable to access services and transport. One third of people with sight loss suffer from depression.

For people with learning disabilities, sight problems can make these issues worse, lowering self esteem or self confidence,<sup>15</sup> and impacting on independent living skills, mobility and communication.<sup>16</sup> People with learning disabilities have as much right as anyone else to emotional support, rehabilitation, low vision support or new technology to help live independent lives if they experience sight loss.

People with visual impairment may also be more likely to have trips or falls<sup>17</sup>, or accidents. If a person has a serious problem but cannot communicate it (such as a sudden change in vision or painful eyes), there is evidence it might be a trigger for self

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<sup>14</sup> RNIB (2015). My Voice. The views and experiences of blind and partially sighted people in the UK. John Slade and Rose Edwards.

<sup>15</sup> Stanford and Shepherd (2001). A vicious circle: visual impairment in people with learning disabilities. *Nursing Times*, 97 (32): 36 – 37.

<sup>16</sup> Evenhuis H M et al (2009). Does visual impairment lead to additional disability in adults with intellectual disabilities? *Journal of Intellectual Disability Research*, 53 (1): 19 - 28.

<sup>17</sup> Dhital A, et al (2010). Visual loss and falls: a review. *Eye*, 24: 1437 -1446.

injury or challenging behaviour.<sup>18</sup> This may then put the person at risk of admission to high cost institutional care.

In 2013 it was estimated the NHS spends £2.64 billion directly on problems related to vision<sup>19</sup> but the economic consequences of not preventing sight loss are clearly much wider, something the RNIB has calculated as high as £22 billion a year for the UK.<sup>20</sup>

### **Further reading**

Read more online about Vision 2020 UK

[www.vision2020uk.org.uk](http://www.vision2020uk.org.uk) and the UK Vision Strategy

<http://ukvisionstrategy.org.uk>

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<sup>18</sup> De Winter, C et al (2011). Physical conditions and challenging behaviour in people with intellectual disability: a systematic review. *Journal of Intellectual Disability Research*, 55 (7): 675 - 698.

<sup>19</sup> RNIB (2013). *Sight loss UK 2013: The latest evidence*.

<sup>20</sup> Access Economics, for RNIB (2009). *Future sight loss UK*.

## **Actions that can prevent sight loss**

### **Key message**

**For people with learning disabilities the key to preventing sight loss, and making the best use of sight, is to have a regular sight test. Some children and adults will also be invited to have their vision screened, and people may also get their eye care in hospital. Questions should also be asked about someone's vision in their annual GP health check.**

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### **The primary care sight test**

This is the main way for people to get their vision and eye health checked and corrected/treated. Free NHS sight tests are available for eligible groups including:

- Children and young people in full time education under 19 years of age and people aged 60 and over
- Those who are registered blind or partially sighted (or in need of a complex lens voucher for glasses - this applies to very high powered glasses)
- Those who have diabetes and those suffering from or predisposed to glaucoma (for example a close family member with the condition).
- People in receipt of certain benefits related to low income and those in receipt of NHS certificates for help with health costs.

It can be noted from the rules above that working age adults with learning disabilities may receive their sight test for free on the NHS, but **it is not an automatic right**. If someone needs glasses they may be eligible for vouchers which can then be used in whole or part to pay towards the costs of these.

The recommended sight test interval is usually two years for adults and one year for children.<sup>21</sup> 12.8 million NHS sight tests were provided to patients in England during 2014-2015.<sup>22</sup> In England the majority of examinations are performed by community optometrists based in practice settings under what is called the General Ophthalmic Services or 'GOS' Contract. People can also pay privately for sight tests although there is no national data collected on the numbers. It has been estimated this leads to an additional 5-6 million sight tests each year.

Usually, sight tests take place at a community optical practice, although there is provision for mobile sight tests where an optometrist can visit someone's home (including residential care) or at a day centre if that person has a disability which means they are unable to leave home unaccompanied. People may also receive their glasses from dispensing opticians, who have advanced competencies to dispense glasses, contact lenses and low vision aids.

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<sup>21</sup> Department of Health, Association of Optometrists, Federation of Ophthalmic and Dispensing Opticians. Memorandum of Understanding Frequency of GOS sight tests (2002).

<sup>22</sup> Health and Social Care Information Centre (2015). General Ophthalmic Services activity statistics - England, year ending 31 March 2015.

## **Secondary eye care**

People may also have their sight tested and vision examined in secondary (hospital or community clinic) care and in some areas services reach out beyond the clinic.

A range of eye care professionals will treat patients with learning disabilities in clinics, including orthoptists specialising in eye movement disorders and vision, hospital based optometrists and dispensing opticians, ophthalmologists – ‘eye doctors’ – who will undertake more complex treatment or surgery, as well as ophthalmic nurses to support treatment. People may also be able to have their glasses or other aids dispensed at hospital or a clinic, or they may be given a voucher for use at a community optical practice.

## **Screening programmes**

Sight problems which are not picked up early on in life can lead to permanent damage. Because of this an orthoptic led vision screen within the ‘school entry health check’ for 4-5 year olds is recommended by the National Screening Committee, and is commissioned by local authorities. A vision screen is not a full eye examination, so concerns will lead on to referral as appropriate.

Because diabetes can cause sight loss (diabetic retinopathy) a NHS Diabetic Eye Screening Programme was announced in 2003. At present, everyone aged 12 and over with diabetes is offered screening once a year. However this does not replace the need for a sight test, and not all elements of eye health are checked.

## **Annual health checks**

People with learning disabilities may receive an ‘annual health check’, where GP practices are remunerated for undergoing appropriate training and completing health checks. While GPs are not responsible for sight tests, the check has a section where people are asked about their eyesight.

### **Further reading**

NHS choices publishes more information on rights to NHS services and screening. See [www.nhs.uk](http://www.nhs.uk)

## **Case study: The benefits of eye care**

Because Lorraine has Down's Syndrome, she has a higher risk of sight problems. In fact she has keratoconus, nystagmus, dense cataracts in both eyes and high shortsightedness.

A few years ago staff at the nursing home where Lorraine had moved temporarily didn't know the extent of Lorraine's sight problems. Lorraine became very withdrawn and didn't want her eyes checked. SeeAbility was asked to become involved and, after securing a domiciliary sight test, Lorraine was put forward for surgery for her cataracts.

The process took a long time because of the need to consider reasonable adjustments and consent, and the right preparation for Lorraine. After a few false starts and negotiations over her support within hospital, including in the post-operative phase, these issues were overcome.

Lorraine did have surgery and happily regained some sight.

The next priority for Lorraine's family and support network was to find Lorraine more suitable accommodation. Lorraine has now moved to a SeeAbility service where she has made friends, regularly gets involved in community activities and is getting the right support including input from rehabilitation workers who can help support her self confidence to make the best use of her vision.

Lorraine's quality of life has much improved since surgery and she has become much more comfortable with having sight tests so her eye conditions can continue to be regularly monitored.

## **Part 2: Issues and experiences**

## **Are people with learning disabilities receiving the eye care they need?**

### **Key message**

**Although no national data is collected, studies show that people with learning disabilities are often missing out on eye care and treatment. In a recent study 50% of people had not had a sight test in the recommended period. Over half of people with learning disabilities have said they were not asked about their vision in their annual health check. 43% of children tested in special schools by SeeAbility have no history of eye care.**

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It is very difficult to find out if all people with learning disabilities are getting access to eye care because generally the both eye care data **and** learning disability data collected across the NHS is poor.

We simply don't know how many people with learning disabilities are visiting community optical practices or getting their eyes tested at home, or in residential/day care settings.<sup>23</sup> There is no national record of how many people with learning disabilities are being treated either as an inpatient or outpatient in hospital eye clinics.

We do know there are people who are getting good eye care from individual professionals, practices and clinics and we

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<sup>23</sup> Hansard. Written question 225540, answered 5<sup>th</sup> March 2015.

celebrate some of the good work that is being done in Part 3 of our report.

And in our survey, we were also told by people that they had had good experiences.

“I have a very good local optician I have been going to since I was young”

“Very polite and patient with me”

“My son’s eyes are tested by the local hospital eye unit. No anxiety, they are amazing!”

However we also know that many people with learning disabilities are missing out on the eye care they need when compared with the general population. There are a number of areas where people with a learning disability seem to miss out.

### **Not accessing sight tests**

SeeAbility ran an easy read survey with people with learning disabilities for the purpose of this report.<sup>24</sup>

The survey did reflect more experiences of adults with mild or moderate learning disabilities than those who have severe learning disabilities and there was potential survey bias in that some of the respondents were from advocacy and peer to peer groups which SeeAbility has worked with to improve uptake of sight tests.

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<sup>24</sup> 458 adults with learning disabilities took part including at SeeAbility events.

63% of people responding had a sight test in the last two years. 10% were outside of the two years, 12% said it was more than five years ago or not all. The remainder of people responding did not say or could not remember when their last sight test was.

In other studies rates of people missing out on sight tests were higher:

- In a West London sight testing pathway<sup>25</sup> for people with learning disabilities, 50% of patients with learning disabilities said the date of their last sight test was over two years ago or unknown.
- In a study in Hackney supporting 28 people to have an eye test, 18% had not had their eyes tested before, while a further 29% had not had an eye test in the past two years.<sup>26</sup>
- A telephone survey of nearly 150 adults in Manchester with learning disabilities found 39% were receiving sight tests less frequently than the recommended two years.<sup>27</sup>

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<sup>25</sup> SeeAbility's pilot of the LOCSU Community Eye Care Pathway for Adults and Young People with Learning Disabilities in the Tri-Borough area of Kensington and Chelsea, Hammersmith and Fulham and Westminster.

<sup>26</sup> Hilary Young (2013). Valuing Vision: Evaluation of an eye care project for people with learning disabilities in Hackney. SeeAbility and Homerton University Hospital NHS Foundation Trust.

<sup>27</sup> Starling, S et al (2006), 'Right to sight' Accessing eye care for adults who are learning disabled. Journal of Intellectual Disabilities 4: 337-55.

- In a Berkshire study<sup>28</sup> there were people with learning disabilities who were having their first eye test in age ranges of 40 – 60 years of age.
- In SeeAbility's special schools work we found 43% of children we tested had no history of eye care. Many of these children had autism, and we were giving many autistic teenagers their first sight test.

There are concerns about uptake of sight tests more generally<sup>29</sup>, but the particular concern from these figures are that people with learning disabilities are highly likely to have sight problems that need treatment or more frequent checks.

### **Not accessing the right glasses or tolerating them**

The studies highlighted in the previous section have also shown the high need for glasses, for example in West London 6 in 10 people received new or replacement glasses. In SeeAbility's special schools project last year 33% of the new pupils we saw needed glasses, 18% needed glasses for the first time or a change of prescription and the remainder replacement for fair wear and tear.

Indeed 70% of those responding to our survey who had a history of previous eye care said they needed glasses. It was good to see the majority of people did say they knew when to wear their glasses (92%). However, ensuring people receive or wear their glasses can be a major issue. In our survey when

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<sup>28</sup> Codling, M et al. (2013) 'Eye Know': translating needs from annual health checks for people with learning disabilities to demand. *British Journal of Learning Disabilities*, 41 (1) 45-50.

<sup>29</sup> Health survey of general population England (2013). Chapter 3 Eye Care.

asked if they had problems with their glasses, 40% of people said they cost a lot and over a quarter said they were uncomfortable or broke too often. 18% said they didn't help them to see. Some people said they lost their glasses, or forgot to wear them and one even said they had been called names for wearing them.

In one piece of research, only one in five of people who needed glasses actually had them.<sup>30</sup> In another study<sup>31</sup>, only 43% of those previously prescribed glasses wore their glasses, something the authors attributed to lack of follow up support.

In Tower Hamlets, in 2009 the PCT commissioned a study<sup>32</sup> of glasses used by people with learning disabilities and found that prescriptions were not picked up, messages on use of glasses were 'lost' between sight tests or not well understood by people supporting that person, or if free, aesthetics and comfort were limited in the choice available for the person. There were immediate barriers getting spares or repairs when glasses were frequently broken.

## **Problems with glasses from an early age**

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<sup>30</sup> Woodhouse et al, A. (2000), The prevalence of ocular defects and the provision of eye care in adults with learning disabilities living in the community. *Ophthalmic and Physiological Optics*, 20: 79–89.

<sup>31</sup> Starling S et al (2006), 'Right to sight' Accessing eye care for adults who are learning disabled. *Journal of Intellectual Disabilities* 4: 337-55.

<sup>32</sup> Leigh Harris (2010). Glasses for people with learning disabilities. Report commissioned by Tower Hamlets PCT.

We also asked parents about their experiences of getting eye care for their children. 179 parents responded to this survey, and many were parents of children with Down's Syndrome. Six in ten of those responding said their child did need glasses.

While parents felt they knew when their child needed to wear their glasses, parents also said their child refuses to wear their glasses (37%), that glasses break too much (35%) or their child finds them uncomfortable (30%). There were also many comments about the frames not fitting correctly and slipping down their child's nose.

A number of parents had clearly tried many different ways to get the right glasses for their child, even though children are entitled to free glasses vouchers. There were frequent comments about the limitations of the NHS voucher scheme.

“I need to have one or two spare pairs to cope with the losses and breakages but the NHS do not provide this.”

“My son – a two year old – manages to scratch the lenses very quickly. I changed his lenses two week ago, paid for a treatment which guarantees no scratches in two years, and they have already been scratched! The amount we receive from the NHS does not pay at all for these frames.”

### **Missing out on population wide health programmes**

While the GP annual health check is an excellent initiative, only around half of people with learning disabilities eligible for this

check might receive them.<sup>33</sup> Prompts on vision and getting a sight test are listed in the annual health check, but it seems people are still not being told about sight tests.<sup>34</sup> For example in one evaluation of health check data<sup>35</sup> only 44% of people were asked about sight.

There is also evidence that diabetic screening, while offered, can fail to adequately monitor people with learning disabilities particularly in terms of actually enabling people to complete the examination.<sup>36</sup>

Meanwhile implementation of the school entry vision screening programme is patchy. In a recent Freedom of Information request, 45% of councils have said they don't commission a service or believe it to be outside of their responsibility.<sup>37</sup> Where

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<sup>33</sup> Glover, G et al. (2013), The uptake of health checks for adults with learning disabilities: 2008/9 – 2012/13. Improving Health and Lives.

<sup>34</sup> Codling, M. (2013), 'Eye Know': translating needs from annual health checks for people with learning disabilities to demand. *British Journal of Learning Disabilities*, 41: 45–50.

<sup>35</sup> Buszewicz, M et al (2014), Assessment of an incentivised scheme to provide annual health checks in primary care for adults with intellectual disability: a longitudinal cohort study. *The Lancet*. Vol 1 December 2014.

<sup>36</sup> Pilling, R. (2015), Screening for diabetic retinopathy in adults with learning disability: current uptake and adjustments to facilitate equality of access. *British Journal of Learning Disabilities*, 43: 62–65.

<sup>37</sup> Clinical Council for Eye Health Commissioning (unpublished) Freedom of Information request.

services are absent it affects all children, including children with learning disabilities.

## **Undiagnosed or untreated serious sight problems**

The result of this unmet need can result in serious sight problems developing with the wider costs to society as outlined in Part 1 of this report.

In a sight testing project in West London<sup>38</sup>, 52% of patients seen had an underlying eye health issue. 33% of patients had a new eye health issue identified, and 30% were referred on to their GP or hospital. The most common issues identified were high intraocular pressures (suspicion of glaucoma) and lens opacities. Significantly 10% of patients were referred on for cataract surgery.

Eye clinics in England are currently struggling to meet demand, and with follow ups delayed there are real concerns this is leading to preventable sight loss.<sup>39</sup> This affects all users of hospital eye clinics, some of whom could be people with learning disabilities.

“Hospital takes ages to fit me in. Follow up appointment 15 month wait so far”

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<sup>38</sup> See Ability’s pilot of the LOCSU Community Eye Care Pathway for Adults and Young People with Learning Disabilities in the Tri-Borough area of Kensington and Chelsea, Hammersmith and Fulham and Westminster.

<sup>39</sup> See Royal College of Ophthalmologists briefing [www.politicshome.com/news/uk/health-and-care/opinion/royal-college-ophthalmologists/73101/eyesight-threatened](http://www.politicshome.com/news/uk/health-and-care/opinion/royal-college-ophthalmologists/73101/eyesight-threatened).

## **Sight Impairment Certification not taking place**

This is important to know because certification can help onward access to benefits and services. Recent research by RNIB indicates children with complex needs and who are eligible are not always being referred for a Certificate of Visual Impairment (CVI) that would help them access services to support them in social care, welfare and education.<sup>40</sup> There is no information on the situation for adults however.

## **People getting routine eye care in hospital**

For the most part, people answering our survey were last seen in a community optometrist, although 12% said their last sight test was at a hospital eye clinic. This rose to over 20% for people who had more severe and profound learning disabilities.

This could be due to genuine clinical need but there may be some people who are using hospital for routine eye care because it is felt there is no community alternative or that testing in the community hasn't been possible. SeeAbility has observed this in the cases of children who we test in special schools, 49% of whom last year were under hospital care. In some of these cases hospitals have now been able to discharge to SeeAbility for routine care.

In our survey with parents, many did say their child was seen at hospital. There were comments about being referred on to hospital because local practices were unable to test.

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<sup>40</sup> Boyce, T (2015). Ensuring Support: Certification and Registration in Children and Young People with Vision Impairment in England. RNIB.

“I was referred to Moorfields eye hospital as he would not sit still for the tests.”

## **Case study: Sally's story**

Sally is in her thirties, and lives with her family in East London. She has a rare genetic condition called 18P Syndrome. Some years ago Sally started rubbing her eyes and described an 'itch' on her head, her way of saying she had a headache. The GP prescribed drops for hayfever and looked into whether Sally had a thyroid or scalp problem.

Then one Christmas, Sally's brother handed her a sweet and mum Maureen noticed she missed it. She thought there may be a problem with Sally's vision and arranged for Sally to have a sight test at home. The optometrist found Sally had extremely high pressures in both eyes due to glaucoma and recommended Maureen take Sally to A&E immediately.

Sally was urgently referred to Moorfields Eye Hospital where different treatment options were considered. Despite successful surgery to drain fluid from Sally's eyes and Maureen helping Sally with eye drops as crucial treatment in the months after the operation, she had already lost most of her vision. Sally can now only see light and dark.

Maureen says:

"We feel guilty about Sally's eye condition and we wish we'd noticed it earlier. I hadn't been told that Sally's type of learning disability might come with an increased risk of developing glaucoma, something we now know. There are times when Sally gets down and realises what she has lost, but we are a loving and supportive family and we do our best to pick her up.

The day centre has also been marvellous adapting for Sally's needs too.

I was so determined something positive should come out of our experience that I started taking part in training events and local vision strategy meetings to call for better awareness and eye care services for people with learning disabilities.

The result is that for the past few years there has been a pathway of eye care for adults with learning disabilities in Barking and Dagenham, which is helping optometry services identify people like Sally at risk of losing their sight, so they can prevent this happening to others. Optometrists also visit Sally's day centre and have found people with glaucoma and cataracts who they didn't expect to have them. People are now wearing glasses that they never had before.

Those visits mean not only have I noticed a difference in Sally, who is more relaxed about her eye checks and confident about going to hospital appointments, I have seen other people in the day centre feel more confident about sight tests too."

## **Why are people with learning disabilities not accessing eye care?**

### **Key message**

**There are many reasons why people with learning disabilities can end up without the eye care they need. Some of this is related to awareness about how a sight test might help a person, some of it is related to a lack of reasonable adjustments, and some of this is related to the experience of eye care staff. The NHS England funding and contract system is set up to meet people's needs is a serious issue.**

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### **i) Awareness issues**

#### **Good sight means healthy eyes?**

There is evidence that lack of funding or other aspects of healthcare might be prioritised over sensory checks which are seen as 'non life-threatening'.<sup>41</sup> People may think good sight means your eyes are fine and don't need checking, or may not know eye tests can detect underlying health conditions,<sup>42</sup> a

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<sup>41</sup> Newsam et al (2010). Sensory impairment in adults with intellectual disabilities – an exploration of the awareness and practices of social care providers. *Journal of Policy and Practice in Intellectual Disability*, 7(3): 211 - 220.

<sup>42</sup> Codling, M et al. (2013) 'Eye Know': translating needs from annual health checks for people with learning disabilities to demand. *British Journal of Learning Disabilities*, 41 (1): 45 – 50.

view held amongst the general population too.<sup>43</sup> Some people said in response to the survey that their eyes were fine and they were not bothered about sight tests.

### **Vision problems overlooked**

Reporting sight problems is known to be symptom led, but if someone has more profound disabilities and cannot speak they may not be able to recognise or communicate those symptoms. This means those supporting people with learning disabilities need to be aware of tell-tale signs of possible problems with vision and make sure people are supported to get a sight test, and to wear and look after their glasses, if they are needed. Otherwise the danger is a change of behaviour could be assumed to be due to someone's learning disability or autism:

“Justine has severe learning disabilities. She started to get angry and upset a lot. She didn't want to go out. Her doctor changed some of her tablets thinking it would help but it didn't. Justine's support worker helped her get an eye test which found her sight had got worse. Justine now has new glasses, she isn't upset any more and likes to go out. Her blurred vision had been the problem.”  
(from Valuing Vision Hackney study)

Sometimes assumptions are made on behalf of the person, for example that you have to be able to read or speak to have a

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<sup>43</sup> Leamon S et al (2014) Improving access to optometry services for people at risk of preventable sight loss: a qualitative study in five UK locations. *Journal of Public Health*. pp. 1 – 7.

test, and even that the person wouldn't see any benefit from having glasses<sup>44</sup> without any real attempt to try:

“Sophie had her eyes tested 15 months ago and it was found she was shortsighted, however due to her profound learning disabilities we (the optometrist and support worker) decided not to prescribe her glasses.”  
(from Valuing Vision Hackney study)

Even if someone is totally blind, they will still need eye health checks as their eyes could be causing them pain and these checks can uncover other health issues.

### **Worries about what will happen or where to go**

Some people answering our survey said they felt nothing had put them off having a sight test. But for others, they were worried about not being able to read (37%), needing more support (36%), and what the tests would involve (29%). Some people were unsure where they could go. Comments ranged a lot and included:

“I might not know the answers. They might not repeat the question”

“Knowing about prices and what you need to put money to”

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<sup>44</sup> Codling, M et al. (2013) ‘Eye Know’: translating needs from annual health checks for people with learning disabilities to demand. *British Journal of Learning Disabilities*, 41 (1): 45-50.

“I need to go somewhere quiet and I have anxiety problems. I find it difficult waiting in a waiting room especially with other people.”

“I am worried I may get an eye infection”

Around two thirds of parents responding said they had been put off taking their child for an eye test. Of these 39% said it was because their child would get stressed and anxious. Around a third said they had communication concerns –that their child couldn’t speak or read, or the professional would find it difficult to communicate.

Almost everyone said what would help them most was to be given time and patience and having things explained to them. It would also help to know they didn’t have to be able to speak or read (38%) or if they could visit beforehand (30%).

Some people made some helpful suggestions about this idea:

“Maybe on the website have a little video with the person who will be there, smiling, saying ‘hello, we are all looking forward to you coming for a test either on your own or with some support’.”

For children with learning disabilities, the majority of parents (70%) said the thing that would help them most was for their child to be given time and patience. Equally the issues of communication came up again, knowing their child didn’t have to read, or speak, and that things would be explained to them as parents. There was also a keenness (37%) to know “where is a good place to go?”

## **Not knowing about home visits**

There appears to be low awareness of the possibility of home visits amongst many disabled people, most recently reported in a study of those with dementia.<sup>45</sup> A number of people with learning disabilities wanted to have information about having an eye test at home (28%).

Some family carers felt that their loved one would never be able to cope in a community practice, particularly if they had autism. As one family carer said:

“The possibility of house visits could be of real benefit to many, providing the service and equipment are of the same standard as in the shop. This option could alleviate some of the stress for many.”

Without this information people may end up going to their GP or seeking out hospital eye clinics, if they feel the community alternative will not meet their needs. This could add to the pressure that hospital eye clinics and general practice are already under.

## **Offputting experiences**

People with learning disabilities often single out some of the tests involved in eye care as problematic. Time and again, people say that eye drops have put off people with learning disabilities from having further eye care. Some people also reported the puff of air test for eye pressures and bright lights had also put them off.

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<sup>45</sup> Hancock et al (2015). A proposal for a UK Dementia Eye Care Pathway. *Optometry in Practice*. 16 (2): 71-76.

“I had air puffed in my eye didn’t like it. I got up and walked out. They did not tell me it was happening.”

In our survey although it was rare, a few individuals did sadly they say they did not have a good experience at the opticians or hospital eye clinic.

“They had no simplified way to test for reading glasses. They pointed to the increasingly small print and just said “can you see that?” ....when I couldn’t get my chin on the rest the optician gave up”.

“A discriminating eye consultant who said it wouldn’t make any difference and didn’t do any tests/measurements after my son had had eye drops. Got to see a different consultant who was much more inclusive.”

### **Concerns about cuts to support and costs**

Nearly half of respondents to SeeAbility’s survey commented that being able to get to the test easily was important to them as well as having their supporter with them (70%). However 36% had been put off through a lack of support. The impact of cuts could mean people are having to choose and prioritise. One care manager said:

“Some of the people we support only receive an average ten hours a week to do everything from cleaning, shopping, medical appointments, correspondence, banking and their support time is a premium so they have to make choices. General eye checks may get neglected especially when thinking about location of services.”

People with learning disabilities are more likely to be in poverty than their non-disabled peers and knowing sight tests might be free is very important too. In our survey when asked what would help a person have a sight test, around half of people with learning disabilities wanted to know if it would be free (54%) and others had worries about the cost of glasses and breaking them.

## **Case study: How eye examinations are possible without using conventional tests**

Lisa is an optometrist who works for SeeAbility on its Children in Focus Campaign, providing sight tests in special schools. Lisa regularly tests children with profound and complex needs, who may be non-verbal, such as Karen.

Karen has a genetic condition called Cri du Chat syndrome that means she needs a wheelchair and has limited movements. She doesn't talk and can't tell people if her vision is blurred. Before having an eye test via SeeAbility at her special school, no-one knew that Karen needed glasses. Karen communicates through eye pointing so clear vision is vital for her.

Lisa says: "When a child is unable to sign or communicate I use a number of techniques to find out what they can see and how well they can focus. This involves observing how they use their vision – can they track a moving object, do they notice objects in their peripheral vision, can they distinguish pictures and colours on some of the materials we use.

We don't need to be in a completely dark room, to use letter charts and for someone to sit still in a chair, for example.

I can get a look at how well a person might be focussing from a distance using my retinoscope.

Having someone present who is familiar with the person, and learning more about what makes the person feel comfortable is key. It might be music or a favourite toy or object. Demonstrating and explaining everything I am going to do before I try to do it often really helps too.

And of course it helps that school is a familiar place for the children we test. We can use the cosy corner of the schoolroom for example.”

## **ii) Reasonable adjustments in practice**

Many Learning Disability Partnership Boards self assess how well health and care services are doing to make reasonable adjustments in practice. In a recent report,<sup>46</sup> looking at NHS commissioned primary care, only 20 of 145 responded on how well optometry was doing. Two areas rated themselves as doing well across the board, meaning all people with learning disability were identified and all services were able to provide reasonable adjustments. The remainder rated themselves as ‘amber’, indicating there is more work to be done at a system level and within individual settings.

### **Identifying people and asking about their needs**

A small survey of 48 optometrists from across five Clinical Commissioning Groups including independent, multiple and domiciliary providers, has been undertaken in Tyne and Wear.<sup>47</sup> 77% of those responding said that their practice did not have a way of flagging patients with learning disabilities records so staff are aware before seeing the person and for audit purposes. In our children’s survey only 12% of parents could recall being asked about any particular needs their child had before going into the eye test.

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<sup>46</sup> Improving Health and Lives (2015). Findings from the 2014 joint learning disabilities self assessment framework. Gyles Glover and Sebastian Fox.

<sup>47</sup> Contact Stephanie Cairns of Northumberland, Tyne and Wear Local Optical Committee for more information – email [stephanie.cairns1@nhs.net](mailto:stephanie.cairns1@nhs.net).

If optometrists aren't aware in advance that people might have a learning disability, this reduces the likelihood of them being able to put in reasonable adjustments in advance.

### **Adjustments at the test**

Almost everyone with a learning disability said what helps them at a sight test is being given time, but it was clear from the survey of experiences this remains a real issue even for those who are more able to advocate for their needs. In some cases people said the environment had caused them problems, such as a long wait in a hospital eye clinic, or having enough space in a community practice. 39% of people in the adult's survey recalled having been shown pictures rather than letters to check what they could see (although not everyone responding may have required pictures).

### **Accessible information**

Around half of adults responding to SeeAbility's survey could recall being told how long to wait before their next eye test and there were some comments about being able to understand information given at the appointment.

“I don't understand my prescription. I always mean to ask. It would be good to get more information on that.”

Fewer people (25%) said they were given information in easy read, although 47% said this is what would help them have a sight test. A lack of easy read information was also a key finding of self-advocacy group Speakeasy N.O.W's work in Worcestershire (see Part 3 of this report).

A quarter of parents responding to SeeAbility's survey, whose child had had a sight test, were not sure what their child could see. Around a third of parents felt they were given helpful information after the sight test on what their child could see (29%).

## **Case study: Lesley's story**

Lesley is mum to a young woman with learning disabilities and autism. Lesley asked for her name to be changed for this report, but wanted us to share her story.

Lesley says:

“Since a young age my daughter has had her eyes tested at hospital. She has monocular vision, astigmatism and has had two operations for a squint.

She has had to have eye drops – until recently on an annual basis. These are painful and traumatic, and stressful for the person administering them. It could be done at hospital but I wanted to avoid her associating hospital visits with pain and her being upset there. I never mention the eye test is due, and try to book for the morning, so I can put the drops in at home with less warning and less distress for her. Reassurance and a cuddle help.

A suitable waiting area is so very important as waiting is not easy as my daughter does not have a sense of time. It is important that enough time is allowed for the test to be done by someone experienced and with an understanding of the needs of people with learning disabilities or autism.

Things have changed recently. She saw the same professional for over 25 years – he was patient, kind, thorough and mindful of my daughter's needs.

His successor was a little perplexed when we first saw him, as if he had not been expecting to see an adult with a learning

disability. Appointments changed to two yearly, and the last check was with another professional who was unusually swift with the test and said they didn't see adults!

I came away thinking that we'll be told to go to a high street opticians next and I have no idea how that would work. However good they may be they are retail environments, and can be very busy or claustrophobic with little privacy.

It is hard to believe there isn't an alternative to eye drops given the distress they can cause, especially for those unable to understand the reason why it is happening. I really hope that technology can be used to remove the need for drops at the earliest opportunity."

### **iii) Experience and training**

Some time ago a study by Mencap<sup>48</sup> estimated that sight testing people with learning disabilities may be about 1% of an optometrist's workload and that some optometrists were not aware of specific visual conditions associated with learning disability. Training that had been received on learning disabilities had been in post qualification.

While this picture may have changed for the better in recent times, when SeeAbility has spoken to colleagues in the sector they confirm the numbers of people with learning disabilities being seen in community optical practices or hospital eye clinic can vary greatly.

In the Tyne and Wear survey of 48 optometrists across independent, multiple and domiciliary providers, the numbers of patients with learning disabilities the optometrists recalled seeing in a year varied – from a handful, to over 50 people.

If an eye care professional has not had experience in treating a patient with learning disabilities they may feel ill-equipped in supporting the person, particularly if the patient has not been 'flagged' on their system beforehand.

There are skilled and experienced professionals, as highlighted in Part 3 of our report. But even so, people may not be aware of

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<sup>48</sup> The NHS Health for all? People with learning disabilities and health care, a Mencap report (June 1998).

their services. In the Berkshire study<sup>49</sup> there were optometrists experienced and skilled in working with people with learning disabilities, but they had very little profile amongst the learning disability community.

People with learning disabilities and family carers also said how continuity of care with the same professional is so important, to build up trust but also understanding.

## **Glasses**

There were also concerns about experience of fitting glasses for people with learning disabilities, if staff change frequently or vary in how often they see someone with a learning disability. People with learning disabilities may need adjustments to fit special facial characteristics, hearing aids or wheelchair headrests, or they might find it difficult to get used to a new prescription, or just need help to understand when they should wear their glasses.

Many people did say that comfort of their glasses was an issue in our surveys. One family carer said:

“I feel many learning disabled people probably end up with prescriptions and frames that are causing irritation and/or discomfort.”

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<sup>49</sup> Codling, M et al. (2013) ‘Eye Know’: translating needs from annual health checks for people with learning disabilities to demand. *British Journal of Learning Disabilities*, 41 (1): 45-50.

The Optician's Act (1989) stipulates that all children under 16 and anyone registered as sight impaired or severely sight impaired can only be fitted and supplied with glasses by a qualified dispensing optician or optometrist. Dispensing opticians are trained professionals registered with the General Optical Council.

However, anyone outside of these groups (which would include a large percentage of the learning disabled population) can have their glasses supplied and fitted by unregistered staff, or even without fitting by purchasing them 'off the shelf' or on the internet.

## **Case study: The skills of a dispensing optician**

Paediatric spectacle dispensing is a highly skilled and complex competency which remains a regulated function in the UK.

Over the past few years the Association of British Dispensing Opticians (ABDO) have made significant progress in raising the awareness of the importance of getting it right first time to ensure the child can make the best use of their sight and are wearing comfortable spectacles.

ABDO came up with the concept of producing anatomically correct paediatric heads of various age groups and differing facial characteristics. Skills workshops have taken place up and down the country to highlight the steps required to fulfil specific patient needs. To successfully dispense spectacles to children, the eye care professional must have a comprehensive understanding of how to measure facial dimensions, particularly the dimensions around the bridge of the nose.

Often, children are seen wearing inappropriate frames which slide down their nose as a result of poor facial fit. Research is sparse however there are now steps being taken to ensure manufacturers develop frames fit for purpose.

ABDO's director of Examinations, Alicia Thompson, is currently working towards a PhD where she will extensively research the facial characteristics of children of various age groups, ethnic groups and other groups in desperate need of properly fitting frames, including children with learning disabilities.

Alicia is working with the Down's Syndrome Association (see Part 1 of this report) mapping the facial characteristics of

children with Down's Syndrome to gather data on how a child's face develops, in particular the nasal area to help develop much better frames for this group of children.

See [www.abdo.org.uk](http://www.abdo.org.uk)

#### **iv) System barriers**

The national NHS General Ophthalmic Services ('GOS') contract and budget allows for many people with a learning disability to have a NHS funded sight test and vouchers for glasses, irrespective of where they live. However, GOS funding, contracting<sup>50</sup> and other pressures can cause inequalities, for the reasons outlined below.

##### **The retail nature of primary eye care**

The GOS fee has remained low for many years (around the £20 level), and much lower than what it really costs to administer a sight test<sup>51</sup>, so practices rely on customers to purchase eyewear (sales being essential for practice viability).

While the retail element has helped make community optical practices a familiar presence on many a high street, this can also be a factor in reducing public inclination to seek sight tests or treat practices as part of the NHS.<sup>52</sup> People with learning

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<sup>50</sup> Shickle et al.(2014), Why is the General Ophthalmic Service Contract that underpins primary eye care in the UK contrary to the public health interest? BJO Online First 1 October 2014.

<sup>51</sup> Shickle et al (2015), Addressing inequalities in eye health with subsidies and increased fees for GOS in socioeconomically deprived communities: a sensitivity analysis. Public Health 129:131-137.

<sup>52</sup> For example, see Hayden, C for RNIB (2012). The barriers and enablers that affect access to primary and secondary eye care services across England, Wales, Scotland and Northern Ireland.

Also see the College of Optometrists, (2016). See the gap – a policy report on UK eye health inequalities.

disabilities have sometimes told SeeAbility they would rather go to the GP or hospital if they had a sight problem, because they are more certain it will be free.

### **A failure to acknowledge additional time in fees**

As highlighted above, the GOS sight test fee has remained at the circa £20 level for many years.

Funding for GOS fails to reflect that people with learning disabilities are likely to need additional time at their test, and potentially more than one appointment to familiarise themselves with the environment and help them complete the tests needed.

### **Ethical considerations**

Some of the testing required under GOS will involve shining a light in a person's eye, and in some cases using drops to dilate the eye to ensure a good view of the back of the eye. This may be too intrusive and distressing for some people with learning disabilities, and indeed other people, such as those with dementia.

If the testing can't be completed, there can be a dilemma amongst practitioners as to what to do next to complete the sight test. In the small survey in Tyne and Wear<sup>53</sup> 61% of practitioners who responded said they would bring a person back for a second unfunded appointment if they felt unable to complete a GOS test. Around 15% said they would refer on to hospital or secondary care.

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<sup>53</sup> Contact Stephanie Cairns of Northumberland, Tyne and Wear Local Optical Committee for more information – email [stephanie.cairns1@nhs.net](mailto:stephanie.cairns1@nhs.net)

These sort of concerns<sup>54</sup>, are heightened if practitioners don't normally see patients with learning disabilities. Professional bodies advise that the person should not examine someone if they do not consider themselves competent to do so, but refer on to someone who is. However interpreted 'to the letter' GOS expects any eligible person to be able to request a sight test from a GOS contractor.

### **The flexibility of GOS to meet needs**

In the two decades since the passing of the Disability Discrimination Act 1995, GOS has remained essentially unreformed. This report goes on to highlight how it was only recently that NHS England accepted that a mobile GOS contractor could operate in special schools, and not just 'day centres', or that it might be helpful for someone with special facial characteristics to be able to get their glasses through GOS, rather than just through the hospital scheme.

Even now, the rules around 'spares and repairs' of glasses are complex. The NHS voucher for glasses only allows for one pair, so people who regularly break their glasses are left without. This then impacts on people's independence while they wait for repairs or for a case to be made for them to have a replacement pair under the NHS voucher scheme. It may mean that people will then need support to get used to their glasses again.

A teacher for adults with learning disabilities told SeeAbility:

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<sup>54</sup> For example see Shah et al (2007). Survey of the availability of state funded primary eye care in the UK for the very young and old. *Ophthal Physiol Opt*, 27: 473-481.

“Many of my students should wear glasses (and struggle in class without them) but they don’t bring them in or don’t seem to get them replaced when lost or broken”.

### **Further reading**

The Foresight Project Report (2016) 2020 Health.  
Commissioned by the Optical Confederation and the College  
of Optometrists.

[www.opticalconfederation.org.uk/activities/foresight](http://www.opticalconfederation.org.uk/activities/foresight)

## **Case study: Using GOS in special schools**

Many of the system barriers are highlighted in SeeAbility's special schools work.

Lisa Donaldson, our clinical lead for our Children in Focus campaign explains how:

“SeeAbility wanted to deliver its special schools work under the GOS contract, as we wanted to ensure that as many children as possible were getting their right to a free NHS GOS sight test in the most convenient and stress-free way.

In some areas secondary care has been able to reach out to deliver eye care in special schools seemingly without the many barriers to getting it off the ground we have experienced with GOS, ironic given GOS is intended as the primary route for case finding and vision correction!

Initially, we were refused a GOS mobile contract on the grounds that a special school could not be considered a 'day centre' – the only community facility for disabled people explicitly listed in the regulations as being authorised for GOS. Eventually we were granted a contract after over a year's wait.

Now we are up and running, we are finding high levels of visual need in special schools that we believe justifies this change of approach:

- Over half of children we tested had a vision problem
- 43% of the new pupils we saw this year had no history of eye care
- 75% of the children with no history of eye care were noted as having autism

- 36% of the children need glasses and the need for strong prescriptions for glasses is also much greater in comparison to mainstream school children
- Only 8% of children had ever had a sight test at an opticians/optometrists in the community

Our work also allows us to show how primary care can provide a community alternative for those children receiving routine eye care from a hospital clinic. For example 49% of the children we tested were under hospital eye clinics, and 85% of those discharged from hospital eye clinics had no follow up community eye care.

However SeeAbility is only paid the current standard GOS fee of £21.31 for a sight test in a special school, which is around a quarter of the actual cost of these tests. We subsidise the remaining costs through charitable funds.

Operating as a GOS contractor is helping us to show NHS England just what needs to change. For example, unlike public health screening which is 'opt out', each patient has to be 'opted in' for their annual sight test, which can lower uptake."

For more information about this work see [www.seeability.org/childreninfocus](http://www.seeability.org/childreninfocus)

## **Part 3: Solutions and good practice**

## **What can people with learning disabilities do?**

### **Key message**

**Being aware that everyone can have a sight test and that you don't have to be able to speak or read is very important. Everyone can look after their eyes and sight with the right help. SeeAbility has lots of information and ways in which we can support people, including advice on where to go for a sight test and if you might have to pay for it.**

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### **Learning to look after sight**

People with learning disabilities are working in groups around the UK to help promote this message, to help spread the word. SeeAbility holds 'Look Here' events for people with learning disabilities to hear more from our own expert by experience, Scott Watkin, about looking after your eyes.

People with learning disabilities and their supporters may not know how to access a service to meet their needs or may be concerned about having a sight test.

So we have made a lot of easy read information available to people with learning disabilities, not just about sight tests, but also about different eye conditions. These are all free.

### **Finding where to go**

One of the big messages from our survey was that people wanted to know where they could go. SeeAbility has a list of

optometrists who have registered on a database to say they can provide support for people with learning disabilities.

### **Providing training and checks on services**

People with learning disabilities are the people who know what needs to change and can self-advocate and educate health professionals about making reasonable adjustments. SeeAbility welcomes feedback about people's experiences too. We can help you, and any group you are part of, to train others as part of our 'Peer Educator Network'.

**Please see the end of this report for more information on all of our resources and for a link to our database of optometrists.**

## **Case study: Bradford People First Peer Educator Network**

Bradford People First is a self-advocacy group for people with learning disabilities. The group works to make the lives of people with learning disabilities better in the Bradford district and throughout the country.

In July 2014 Bradford People First joined SeeAbility's Peer Educator Network. Jane helps the group with its 'Healthy Living' projects and tells us more:

“SeeAbility gave our group ‘Opening Eyes’ training about eye care and vision and now we deliver this training to local people with learning disabilities. The training helps people to feel more confident in looking after their eyes and helps them overcome their fears and anxieties about eye examinations.

Bradford People First are ideally placed to deliver this training as we also understand eye care from the perspective of someone with a learning disability. The training kit includes different sight testing methods and the opportunity to practice cleaning a pair of glasses, a skill we all need!”

See: [www.bradfordpeoplefirst.org.uk](http://www.bradfordpeoplefirst.org.uk)

## **Case study: Speakeasy N.O.W**

Speakeasy N.O.W is a self-advocacy group for people with a learning disability who live in Worcestershire. Their work includes a Health Checkers Project which is about people with learning disabilities assessing the health services that people receive, and the group has already looked at dentists, hospitals and GPs.

Gail Greer, of Speakeasy N.O.W reports on their recent work with looking at eye care: “We visited 12 local high street opticians plus the three specialist ophthalmology departments in Worcestershire hospitals. We spoke to a number of groups and individuals to gather their stories and experiences.

We found there was no easy read information used by opticians and they weren't aware these were available on the SeeAbility website. Opticians also tended to rely on online systems for feedback, or booking home visits, that might not be accessible to most people with learning disabilities. There was a general willingness to make adjustments for people with learning disabilities if required and we heard good examples. All premises were wheelchair accessible but some had very little room for manoeuvre.

See [www.speakeasynow.org.uk](http://www.speakeasynow.org.uk)

## **What can family supporters and care and support services do?**

### **Key message**

**Being aware that everyone can have a sight test and that you don't have to be able to speak or read is just as important for supporters to know as it is for people with learning disabilities. No one expects you to be an expert on vision but there are tell-tale signs of possible problems with vision. Helping people wear and look after their glasses is really important too.**

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In many cases the onus will be on those supporting people with learning disabilities to arrange regular sight tests. For care and support services, the scale of sight problems amongst the people you support could be underestimated.

Look out for possible signs and symptoms that might range from a person eye rubbing, having discomfort with bright lights, being hesitant in poorly lit environments, losing interest in social activities, or bumping into furniture or being alarmed at an unfamiliar noise or when approached. Significant changes in general behaviour, for example challenging behaviour or withdrawal, may also result from a sudden deterioration in vision.

Remember no one is 'too disabled' to have a sight test and it can help a person enormously. SeeAbility can help signpost to optometrists who can support the person. Explain that the person has a learning disability when booking the sight test as

this paves the way for the optometrist to make reasonable adjustments.

Carers and supporters are key in helping the person wear prescribed glasses, so it is important to be with the person to collect their glasses, and look out for tell-tale signs of ill-fitting glasses such as marks on a person's nose or ears or reluctance to wear them. Even the correct prescription can take a lot of getting used to, especially if they are strong or very different to a previous pair.

Support plans can be adapted to help someone get used to their glasses for example by building up to using them for longer periods of time each day or to help them identify which glasses are for which activity (distance or near).

SeeAbility has also worked with a number of care providers on our 'Eye Care and Vision Charter' to help build these key things into staff training and into a person's care plan. The training and planning ties in with accessible easy read information, which can help people get access to sight tests and looking after glasses. The training also helps staff do 'Functional Vision Assessments' using observation to recognise the sight difficulties people with learning disabilities might be experiencing.

## **Case study: Working towards an Eye Care and Vision Charter**

Certitude is a not for profit organisation providing personalised support for people with learning disabilities, autism and mental health needs across London. Over the past year, Certitude has been working towards achieving SeeAbility's Eye Care and Vision Charter for the people it supports in the London Borough of Ealing. The Charter supports social care provider organisations in how they assist people with learning disabilities to look after their eyes and vision.

SeeAbility's work fits in really well with Certitude's co-produced 'Treat Me Right!' Health campaign which works with local healthcare and professionals to improve understanding and communication channels for people with learning disabilities.

Here Elsa Morris, Certitude's 'Treat me Right' coordinator explains more:

"In 2015, Certitude asked SeeAbility to deliver Look Here events in Ealing for the people it supports. At the events, people with learning disabilities learnt more about looking after their eyes.

The events were chaired by Scott Watkin who has a learning disability and an eye condition called keratoconus. Scott has the ideal perspective to communicate important eye care messages to people with learning disabilities.

Following the Look Here events, Certitude services go on to complete a self-assessment in order to achieve the Charter. This partnership with SeeAbility reflects that Certitude is being

proactive in supporting people with learning disabilities to look after their eyes and their general health.”

SeeAbility is happy to hear from other providers who would like to discuss the Eye Care and Vision Charter.

See: [www.certitude.org.uk/find-support/learning-disability/services-we-offer/support-with-healthcare/more-about-tmr-health/](http://www.certitude.org.uk/find-support/learning-disability/services-we-offer/support-with-healthcare/more-about-tmr-health/)

## What can community optical practices do?

### Key message

**It is very important that front of house staff, optometrists and dispensing opticians are aware of their duty to provide reasonable adjustments and new rights that people with learning disabilities have for NHS information to be provided in an accessible format. Professionals can make use of freely available easy read information, as well as guidance from professional bodies.**

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The need for reasonable adjustments is emphasised in the revised General Optical Council standards for optometrists and dispensing opticians.

The College of Optometrists and Vision 2020 UK learning disability sub-committee have produced a self assessment tool to support the provision of services for people with learning disabilities, so optometrists can identify how well their service is working for people with learning disabilities and simple adjustments that can be made.

The more that a practice knows in advance, and encourages people to let them know if they have additional needs, the better the service will be. Pre-test visits or being able to split the test up could well help the person be less anxious and give an idea of what is involved, as well as appropriate testing materials that mean a person does not have to be able to read.

Given the high level of people with learning disabilities in our survey stating their glasses were uncomfortable (28%), it is helpful if dispensing is undertaken by a qualified dispensing optician or optometrist and people get good advice on how to use their glasses.

### **Accessible information**

By 31 July 2016 a person's right to accessible NHS information is also strengthened by a new mandatory NHS standard meaning all NHS providers are required to meet the communication needs of their patients and service users. SeeAbility offers freely available easy read information about having a sight test, and feedback from the sight test, as well as getting used to glasses, that practices can use.

### **Publicity**

Community optometrists who can offer additional support for people with learning disabilities may wish to make these local links and use the registration facility on SeeAbility's database of optometrists (see useful SeeAbility links at the back of this report).

## **Further reading**

Vision 2020 UK Learning Disabilities Committee/The College of Optometrists (2015). Quality Standards for Services for Patients with Learning Disabilities self assessment tool  
[www.vision2020uk.org.uk/quality-standards-for-services-for-patients-with-learning-disabilities/](http://www.vision2020uk.org.uk/quality-standards-for-services-for-patients-with-learning-disabilities/)

Improving Health and Lives (2013). Making reasonable adjustments to eye care services for people with learning disabilities. Sue Turner, Stephen Kill, Eric Emerson.  
[www.ndti.org.uk/uploads/files/IHaL-2013 - 01 Reasonable adjustments.pdf](http://www.ndti.org.uk/uploads/files/IHaL-2013-01_Reasonable_adjustments.pdf)

NHS Accessible Information Standard  
[www.england.nhs.uk/ourwork/patients/accessibleinfo/](http://www.england.nhs.uk/ourwork/patients/accessibleinfo/)

## **Case study: Bringing it all together in Durham**

Simon Berry has been a qualified optometrist for 20 years. He also blogs for the Down's Syndrome Association for its vision month, to help parents understand more about eye examinations and frame fitting. Simon says:

“I started my pre-registration at Sunderland Eye Infirmary and still work two sessions a week as a specialist optometrist. I set up my own optometric practice in Durham in 2002. Our practice has tried to specialise in children's eye care but we also see adults with learning disabilities. I publicise my service on the SeeAbility website.

Working in the two environments of hospital and community practice can also mean you notice where things are going wrong for people with learning disabilities. I questioned why people were able to have frames for special facial characteristics under the hospital voucher system, but not under GOS.

This was an obvious inequality that affects people with learning disabilities from conveniently accessing the frames they needed. At first there was some reluctance at NHS England but we persisted and brought others on board with the campaign, including our local MP, SeeAbility and the Down's Syndrome Association and are pleased to say the rules have now been changed.

Now my work is taking me into a special school, to support the SeeAbility pilot project which has started in Durham.

This is designed to tie in with the work the Durham Local Optical Committee and our Local Eye Health Network

colleagues and commissioners are undertaking to introduce a learning disabilities pathway in the area that will support children in transition into adulthood, so they are able to access regular, reasonably adjusted eye care in local practices.”

See: [www.loc-net.org.uk/durham](http://www.loc-net.org.uk/durham)

## What can hospital eye care services do?

### Key message

**Hospitals can be daunting places for people with learning disabilities. Services can help by proactively identifying if someone has a learning disability, making the use of learning disability professionals and advocates, clinical advice and resources and having good policies and procedures in place.**

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It is important to be aware of the need to offer reasonable adjustments and act in a non-discriminatory way.

Comprehensive guidance for clinics and for surgery/screening practice can be found in The Royal College of Ophthalmologists guidance and a quality standards checklist.

The advice includes flagging if the person has a learning disability to help the person prepare and using pre-visits that might help the person familiarise themselves. Health or hospital passports and sources of advice within the Trust (such as learning disability nurses) can really help in these plans.

SeeAbility has a suite of easy read information that clinicians can use – such as advice on using eye drops, or feedback on the outcome of the appointment, to an eye surgery support plan.

Having well established procedures in every hospital for assessing consent and capacity, so people do not lose the opportunity for eye care treatment and surgery is important, as is exempting people with learning disabilities from 'do not

attend' policies given the likelihood they may have experienced problems in attending. Other important considerations are reducing stress of waits, quiet waiting areas and giving appointments at a time that suits the person.

### **Further reading**

Management of visual problems in people with learning disabilities Ophthalmic Services Guidance

[www.rcophth.ac.uk/wp-content/uploads/2014/12/2011\\_PROF\\_128\\_The-management-of-visual-problems-in-people-with-learning-disabilities.pdf](http://www.rcophth.ac.uk/wp-content/uploads/2014/12/2011_PROF_128_The-management-of-visual-problems-in-people-with-learning-disabilities.pdf)

The Royal College of Ophthalmologists, Vision 2020 UK and SeeAbility, Eye Care for People with learning disabilities

[www.rcophth.ac.uk/wp-content/uploads/2015/09/Eye-Care-Services-for-Adults-with-Learning-Disabilities-2015.pdf](http://www.rcophth.ac.uk/wp-content/uploads/2015/09/Eye-Care-Services-for-Adults-with-Learning-Disabilities-2015.pdf)

## **Case study: Award winning work in Bradford**

The Bradford Learning Disability Eye Service team won the prestigious 'Astbury Award' for Excellence in the eye care sector in 2015. Rachel Pilling, consultant ophthalmologist at Bradford Teaching Hospital NHS Trust describes just what makes the service so special:

“The exciting thing about our service is that it brings together community health, hospital eye service, education, voluntary sector, patients and carers to improve access to eye health for adults and children with a learning disability.

This enables us to work across the whole pathway of care, from an initial assessment, through to consent for treatment, surgery and if sight cannot be restored, onward support to registration and emotional and practical support.

As well as being able to assess someone in their own home, or in a residential home, to preclude a visit to the eye clinic, we have also undertaken dedicated work with our CCG to provide orthoptic led assessment of children attending special schools, meaning teachers are able to find out what a child can see.

We are finding many cases of unmet need and some serious but previously unidentified sight problems. We make use of the SeeAbility eye surgery plan to work with patients who need surgery. One of the most tangible outcomes is that we restored sight in seventeen patients, leading to remarkable improvements in the mobility, self care and quality of life for the patients.

I hope that we can inspire others to adopt the same sort of team approach because with relatively few, simple and largely cost free reasonable adjustments we have demonstrated that patients can have a successful and calm experience. I have undertaken eye examinations in a parked minibus outside the clinic, to bringing a patient through a back entrance to the anaesthetic room to minimise stress and anxiety!

All it needs is a little imagination and an open mind to do things in a way which primarily suits the patient, not the health professional.”

See: [www.bradfordhospitals.nhs.uk/bradford-learning-disability-eye-care-team-win-prestigious-national-award](http://www.bradfordhospitals.nhs.uk/bradford-learning-disability-eye-care-team-win-prestigious-national-award)

## What can other professionals do?

### Key message

**Other health professionals supporting people with learning disabilities, which might include GPs or learning disability nurses, as well as learning disability teams, have a key role to play in being aware that people have a high risk of sight problems and need regular sight tests. It is very important to cover vision in annual health checks and in health action plans, for example.**

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Often the professional the person sees the most often, and who might be in the best position to pick up on vision problems is the person's GP – particularly at their annual health check. People with learning disabilities may also be in touch with health facilitators and learning disability nurses based in community teams.

The annual health check should lead to a health action plan for the person with learning disabilities. GPs should ensure that every check covers the section on vision and the need to go to regular sight tests in their health action plan.

When making referrals, ensure the eye clinic or practice knows the person has a learning disability. It can also help to know there are local optical practices which can support people with learning disabilities, which are available on SeeAbility's website. This may also save on any need to refer to a hospital eye clinic.

Being aware of signs and symptoms, knowing what vision problems might be linked to the person's learning disability and using easy read information can help. It is also important not to make assumptions about the benefit of eye care or glasses.

SeeAbility would like local learning disability activity and strategies to aim to ensure regular sight tests are given emphasis as well as the annual health check. Learning disability commissioners, partnership boards and local Healthwatch may also wish to find out more about how eye care services are meeting people's needs locally. It is crucial that commissioners fund enough time in support plans for people to access all the medical appointments they need, otherwise they may neglect their sight.

### **Further reading**

Royal College of GPs. Vision and people with learning disabilities

[www.rcgp.org.uk/~media/Files/CIRC/GP%20guide%20for%20vision%20and%20learning%20disabilities.ashx](http://www.rcgp.org.uk/~media/Files/CIRC/GP%20guide%20for%20vision%20and%20learning%20disabilities.ashx)

## **Case study: Breaking down boundaries of care in Torbay**

At Torbay Hospital, Kathy Diplock is an orthoptist with an extended role, co-ordinating services to improve access to eye care for adults with learning disabilities in South Devon.

Kathy encourages people to access primary eye care where possible, and she takes on a bridging role between Primary Care Liaison Nurses in local learning disability teams, GPs and local optometrists and for children in transition, to smooth the links between hospital and community and ensure everyone is aware of the need for regular eye checks.

The service now has defined pathways for the diabetic eye screening service and for desensitisation sessions with the aim that everyone gets reasonable adjustments including easy read appointment letters and double length appointments.

On a broader level she is also liaising with Devon Local Optical Committee to steer the creation of an enhanced eye care pathway for people with learning disabilities and has just finalised a referral pathway allowing community optometrists to refer people directly to local Learning Disability Teams for desensitisation to improve access to primary care.

Kathy says:

“One of the most satisfying parts of my work is helping people with more severe learning disabilities get an orthoptic home eye check, often accessing eye care for the first time in years. For some people, this might mean steering a case through to successful surgery. For others it may mean referring on for

local optometry involvement and so reduce the number of secondary hospital appointments.

Working in this way helps people get used to having their eyes tested, and care staff get to understand how the person can see, how strategies can support them and the importance of follow up care and regular sight tests in the future.

As orthoptists we are in a unique position to help coordinate services because some of the most challenging referrals require that link between community and hospital.”

See:

[www.torbayandsouthdevon.nhs.uk/services/orthoptics/learning-difficulties](http://www.torbayandsouthdevon.nhs.uk/services/orthoptics/learning-difficulties)

## **A note on autism**

Although not everyone with autism has a learning disability research has found that many of the issues raised in this report have a bearing for people with autism.

People with autism also suffer health inequalities and while autism is less associated with serious sight problems than learning disabilities, there is evidence, certainly in children that there will be an increased likelihood of accommodative deficit (the eye's 'zoom' function), and squint and astigmatism are more common.

There is also a risk of diagnostic overshadowing if a person is non-verbal, where sight problems can be mistakenly attributed to autistic behaviours, or a belief that a person may not be able to tolerate a sight test or sustain glasses wear, particularly as sensory needs of people with autism are heightened. Long waits or a busy environment of a clinic or a practice can also be overwhelming.

Work undertaken by Dr Louise Gow, at Action for Blind People<sup>55</sup> has stressed the importance of improved optical professional awareness of autism, and helping a child with autism feel in control of their sight test with personalised adaptations and strategies. Knowing what to expect and feeling in control, as well as being given time, patience and having things explained is a strong

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<sup>55</sup> A qualitative investigation of primary eyecare of children with ASD, Dr Louise Gow, Action for Blind People, oral presentation to Vision 2020 (2014).

comment which came from adults with autism filling in the SeeAbility survey.

New statutory guidance in 2015 to support the adult autism strategy recommends autism awareness training is part of staff training in health and social care. There is some very helpful advice from the National Autistic Society (see further reading) on what to expect from an eye care appointment, and guidance for eye care professionals about treating patients with autism. The Society is also working to make services more aware of autism through its 'autism friendly award' and is working with community opticians to be part of the scheme, with the first award being made to a practice in Scotland in June 2016.

### **Further reading**

For more information and advice see National Autistic Society [www.autism.org.uk/about/health/eyecare.aspx](http://www.autism.org.uk/about/health/eyecare.aspx)

## **What can commissioners do?**

### **Key message**

**Sight loss which could otherwise have been prevented can have a real impact on local health and care costs.**

**Commissioners should work with their Local Eye Health Networks and Local Optical Committees to pilot new ways of working in their areas, including the LOCSU Community Eye Care Pathway for Adults and Young People with Learning Disabilities, which is proving to be successful in tackling unmet need in this high risk group.**

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Clinical Commissioning Groups (CCGs) that support eye care for people with learning disabilities will achieve better outcomes on health related quality of life, improving patient experience, reducing social isolation and injuries due to accidents and falls, ensuring people are being supported to manage their condition as well as reducing preventable sight loss. As highlighted in this report, the local cost attributed to sight problems and issues with local hospital eye clinic capacity should be a concern to every commissioner.

SeeAbility recommends that CCGs, public health and learning disability commissioners take an active interest in eye health and care, and talk to people with learning disabilities and those who deliver primary and secondary eye care in order to identify the improvements needed.

### **Work with Local Eye Health Networks**

Commissioners have a source of expertise and advice in the form of Local Eye Health Networks (LEHNs) who are there to promote strategic approaches to eye care including new approaches to address the needs of people with learning disabilities and other hard to reach groups.

The LEHNs can help commissioners understand how to identify data on sight loss and will have produced their own information on need and priorities, enabling this information to be reflected in other commissioning plans (eg. Joint Strategic Needs Assessments or Health and Wellbeing Strategies).

### **Commission the LOCSU adults learning disability pathway**

In every area there are Local Optical Committees (LOCs), bodies which represent optometrists and opticians to engage with commissioners and ensure there is a role for community optometry in supporting better eye care.

LOCSU is the national support organisation for LOCs and it has developed community pathways that can help commissioners make eye care services more accessible. LOCSU has worked with SeeAbility to develop the LOCSU Community Eye Care Pathway for Adults and Young People with Learning Disabilities.

This pathway utilises accredited optometrists to provide a tailored service to make sight tests more accessible to adults with learning disabilities, for which optometrists are paid an enhanced fee for longer appointments. It makes use of specially designed information and resources to provide and promote enhanced sight tests for people with learning

disabilities, working with individuals, learning disability groups, care providers and advocates to promote the service.

There are now a number of LEHNs and LOCs who are working with health and learning disability commissioners to pilot and implement LOCSU learning disability pathways at a local level and collect robust data on need and outcomes.

The pathway is in place in the London Boroughs of Bexley, Barking and Dagenham and Sutton. Pilots have just started in Greater Manchester and in the Durham area and are in development in Welwyn and Hatfield, and proposed in Cheshire and Mersey.

### **Further reading**

Local Optical Committee Support Unit Community Eye Care Pathway for Adults and Young People with Learning Disabilities  
[www.locsu.co.uk/community-services-pathways/community-eye-care-pathway-for-adults-and-young-pe](http://www.locsu.co.uk/community-services-pathways/community-eye-care-pathway-for-adults-and-young-pe)

More resources are also available on SeeAbility's website for commissioners  
[www.seeability.org/our-services/advisory-services/improving-local-eye-care](http://www.seeability.org/our-services/advisory-services/improving-local-eye-care)

## **Case study: Local solutions to fill national inequalities**

### **West London Tri-borough commissioning area**

SeeAbility secured funding from the LOC Central Fund to pilot the pathway in the Tri-borough area of West London (Kensington and Chelsea, Hammersmith and Fulham, Westminster). The pilot ran from October 2013 to March 2015. The pilot worked with local optometry and learning disability services, learning disability and carers groups, care providers and advocates to set up and promote the service, ensure uptake and gain satisfaction feedback.

As highlighted earlier in this report, the pilot has helped identify unmet need, significantly restoring people's quality of life and eyesight. Following their sight test:

- 33% of patients had a new eye health issue identified
- 63% were wearing prescribed glasses
- 30% were referred on to their GP or Hospital for an eye health or other health issue
- 50% of patients reported the date of their previous sight test was more than 2 years ago or unknown.

### **Greater Manchester**

The 'Devo Manc' agenda has enabled the Local Eye Health Network in the area to secure funding from NHS England to pilot the LOCSU learning disability pathway, equating to 1,600 sight tests. This will inform and provide evidence for having the pathway across Greater Manchester. Children in special schools are also a target. While there are areas of good practice, the work is looking at how to ensure all 98 special

schools in the area are served. For more information see:  
[www.gmpec.co.uk](http://www.gmpec.co.uk)

## **Sutton**

A redesign of the Sutton enhanced optometry service pathway for people with learning disabilities has been agreed and funded by the Sutton CCG since 2014 and following training and promotion, the pathway is now really taking off. Early analysis of the data has identified a number of serious eye conditions, for example, detecting cataracts in 11% of patients tested.

## **Part 4: Recommendations**

## **SeeAbility recommendations for reform**

### **Key message**

**SeeAbility supports the wider calls to reform delivery of eye care. But specific changes that would benefit people with learning disabilities include the introduction of a new national pathway of eye care for adults, a national programme of sight tests in special schools, for all working age adults to become eligible for NHS funded sight tests, and ensuring glasses are fitted by qualified staff.**

**There also needs to be better data collection by the NHS on eye care, training for health and social care staff on the importance of sight tests for people with learning disabilities, supplemented by a new national awareness campaign.**

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There is no doubt that the way eye care is delivered is in need of both reform and investment. SeeAbility supports the calls for better use of primary eye care, multidisciplinary management of patients to release current and future capacity within hospitals and general practice, and for integrated pathways of care at sufficient scale to have impact. There is an urgent need to enable community optical practices to connect to the rest of the NHS and address the void in data collection.

We support the calls for more standardised training and competencies, and a universal recognised national system of further qualifications for each profession to take on expanded roles.

Specific actions that could be taken to support people with learning disabilities are:

### **Introduction of a national adult learning disabilities eye care pathway**

Nationally GOS fees do not recompense or incentivise longer reasonably adjusted eye care in community practices or community facilities exacerbating the health inequalities that people with learning disabilities experience and NHS England is – wrongly in our view – relying on local commissioners to fill the gap in a handful of areas.

NHS England should introduce the LOCSU Eye Care Pathway for Adults and Young People with Learning Disabilities as funded through national enhancements to the GOS scheme. This would ensure people with learning disabilities (with GOS entitlement) have universal access to tailored sight tests by accredited optometrists to meet their needs. This would need to be supported by promotion of the pathway to people with learning disabilities, supporters and other healthcare professionals. We note a similar proposal has been made for a dementia eye care pathway, requiring a revision to GOS to ensure equitable national access to eye care for those with dementia.<sup>56</sup>

Triggered by the introduction of the Accessible Information Standard, NHS England itself has recognised that to have better

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<sup>56</sup> Hancock et al (2015). A proposal for a UK Dementia Eye Care Pathway. *Optometry in Practice* Volume 16 (2): 71-76

communication, people may need longer appointments<sup>57</sup> and that “commissioners should ensure that they support this requirement including through tariffs, contracts and performance-management frameworks with provider organisations.” It does not seem unreasonable to suggest that NHS England – the GOS commissioner – introduces a tariff within GOS that allows for longer appointments.

### **Introduce free sight tests for working age adults with learning disabilities**

Working age adults with learning disabilities are faced by confusing rules on potential entitlement to a NHS funded GOS sight test. We believe all people with learning disabilities should be entitled to a NHS funded sight test as they are at such high risk of experiencing sight problems. We note that other high risk groups (such as those with a family history of glaucoma) are entitled to NHS funded sight tests.

In Scotland, the concerns about means testing have led to a free to all comprehensive eye examination appropriate to a patient’s need, symptoms and general health, at the practitioner’s discretion.

### **A national programme of sight testing in special schools**

With only just over 100,000 pupils in special schools, there also is a strong case for a targeted national ‘opt out’ programme for properly funded sight tests and glasses dispensing in special schools. This would enable children with some of the most profound needs, and therefore most at risk of not getting the eye care they need, to get support in a familiar environment.

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<sup>57</sup> NHS England (2015). Accessible Information, Implementation Guidance. See point 11.4.6

For some children under hospital eye clinics, school will also be a more convenient and comfortable place for them to receive eye care.

The children in special schools would then be able to transition into using a new national adult learning disabilities pathway to continue important checks on their sight after they have left school.

### **Reforms to ensure better access to glasses**

NHS England should undertake a review on how children and adults with learning disabilities, and indeed other groups – such as those with dementia,<sup>58</sup> can get enhanced access to NHS glasses vouchers including automatically being issued with spares, and flexible and more resilient frames in case of damage. The cost of glasses is a real concern to many adults with learning disabilities. Complex means testing rules on glasses vouchers leave some people with learning disabilities unable or confused about whether they can get their glasses for free and many are waiting too long for replacements.

We recommend that dispensing of glasses to people with learning disabilities should be undertaken by a dispensing optician or optometrist rather than unregistered staff.

### **Recording learning disability in eye care data and promoting further research**

There should be a focus on data collection from GOS, Certificates of Visual Impairment, Hospital Eye Clinic records and public health screening programmes to better understand

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<sup>58</sup> Hancock et al (2015). A proposal for a UK Dementia Eye Care Pathway. *Optometry in Practice* Volume 16 (2): 71-76

how people with learning disabilities are accessing eye care and what their outcomes and experiences are.

SeeAbility is keen to see research on the necessity of routine use of eye drops and also into the ethical implications around consent for the administration of eye drops. This is because they so often distress people with learning disabilities and autism and prevent them from taking part in any further eye care.

### **Better training and recognition of the visual needs of people with learning disabilities across health and social care**

The Care Quality Commission should be alert to the eye care needs of people with learning disabilities when inspecting care settings, enquiring whether people have had regular sight tests. Health Education England, Skills for Care and NICE also have a role to play in promoting awareness and good practice in these sectors. Health and social care training should include eye care for at risk groups, particularly as professionals are often the 'gatekeepers' for further screening and treatment.

### **Embed eye care in learning disability programmes and policy**

We would also like to see eye care embedded in national learning disability policy and programmes, as part of the drive towards better health care for people with learning disabilities. This is especially important given there is no parallel NHS strategy for eye care.

For example, the NHS England Transforming Care Programme is targeting people with learning disabilities and/or autism

within, or at risk of admission to high cost institutional settings. We would like to see the programme recognise that a change in vision may be reason for a change of behaviour, and encourage a check on a person's sight prior to their admission and discharge from assessment and treatment units.

On a broader level, for the wider community of people with learning disabilities, new plans and strategies should emphasise the visual needs of people with learning disabilities, and importance of sight tests. NHS England has imminent plans to reform the GP annual health check to ensure there is much greater uptake and we would like to see prompts to go for regular sight tests and questions on vision given new prominence in the check.

The new NHS Quality Checkers Programme is using tools co-produced by people with learning disabilities and/or autism to improve access to NHS services, but only covers primary care in terms of GPs and dentistry, and not optometry.

### **A national awareness campaign**

Policymakers such as NHS England, Public Health England and the Department of Health all hold a variety of responsibilities and should come together to support the messages that no-one is 'too disabled' to have a sight test, the need for regular sight tests and that people with learning disabilities are a high risk group.

Any public health campaign will need to be accessible for people with learning disabilities and engage with advocacy groups and the eye care sector, helping reiterate the message on reasonable adjustments and new Accessible Information

Standards, as well as providing advice on routes to challenge discriminatory practice.

## Conclusion

This report has reflected on the many individuals with learning disabilities, supporters, groups, eye care and learning disability professionals and commissioners who are doing their best to change things for the better for people with learning disabilities.

However, this is happening almost in spite of, rather than thanks to, the current system of eye care in England. The types of eye examinations and services that people with learning disabilities need cannot be delivered under the constraints of the current system.

If the NHS is serious about prioritising the needs of people with learning disabilities, as well as making the best use of its resources, it should look to implement new national programmes and pathways of eye care without delay. By improving things for people with learning disabilities, other at risk groups in the system could also stand to benefit such as those with autism who do not have a learning disability, and those with dementia.

Scott Watkin, SeeAbility's Eye Care and Vision Development Officer, opened this report with his experiences, and he has the final word:

“All the good work helping people with learning disabilities live independent lives in the community is no good if we don't make sure people have a basic right to sight. Even now, and in the job I do, I still hear of people who have never had a sight test because no-one thought it would be possible. It would be great if we could make that a thing of the past.”



## List of SeeAbility resources and support

SeeAbility's accessible easy read information on sight tests and glasses for use by people with learning disabilities, supporters and community optical practices [www.seeability.org/myeyecare](http://www.seeability.org/myeyecare)

SeeAbility's database of opticians helps people understand where they might go [www.seeability.org/find-an-optician](http://www.seeability.org/find-an-optician)

More about hosting a SeeAbility 'Look Here' event for people with learning disabilities is here [www.seeability.org/our-services/advisory-services/look-here-events](http://www.seeability.org/our-services/advisory-services/look-here-events)

SeeAbility's Functional Vision Assessment tool and our training opportunities such as our Eye Care and Vision Charter, or joining our Peer Educator Network are here [www.seeability.org/our-services/advisory-services](http://www.seeability.org/our-services/advisory-services)

SeeAbility's eye surgery support plan [www.seeability.org/uploads/files/PDFs\\_Books\\_Easy\\_Read/ESSP\\_full.pdf](http://www.seeability.org/uploads/files/PDFs_Books_Easy_Read/ESSP_full.pdf)

For more information on our resources please contact our Eye Care and Vision team.

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