

# Improving Eye Care Across Wessex

Understanding the experiences of adults with learning disabilities and/or autism's access to sight tests and eye care

April 2020



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# Executive Summary

This report was commissioned by NHS England Wessex (South) to understand the experiences of adults with learning disabilities and/or autism with sight tests and eye care, especially if people had never been to one and/or have complex needs.

People with learning disabilities and/or autism are more likely to have a sight problem than other people – adults with learning disabilities are 10 times more likely and there is increasing evidence indicating this for autistic adults.<sup>1</sup>

120 adults with learning disabilities and/or autism and 30 carers across Dorset, Hampshire and the Isle of Wight participated in our survey. Approximately 51% of people who participated said they wore glasses. While most had been for a sight test previously, many had not been to one in the recommended two-year period. People described good practice as positive, easy experiences. They made suggestions on possible improvements to help facilitate positive experiences as well. Key factors that influenced a person's experience included:

- Having communication and support throughout the process, including the use of Easy Read resources
- Seeing the same optometrist and staff at each appointment
- Having information about sight tests and good eye care, including domiciliary tests

No one is too disabled to have a sight test and with the right support, more people can get the eye care they need. We recommend a number of short- and long-term solutions to help improve access and uptake of sight tests for people with learning disabilities and/or autism, including:

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<sup>1</sup> The conditions are often co-occurring with approximately 20-30% of people with learning disabilities also having autism. Source: <https://www.england.nhs.uk/wp-content/uploads/2020/01/Learning-disability-and-autism.pdf>

- Increase general awareness of sight tests and good eye care
- Ensure optometrists and optical staff receive relevant awareness training and use reasonable adjustment flags to help meet people's specific needs
- Ensure Annual Health Checks are effective in addressing eye health
- Develop a learning disability and autism standard for optometrists and optical staff that is quality checked by local learning disability user-led groups
- Use the findings of this report to support the call for more dedicated eye care schemes for this group – ideally nationally but in the absence of this, create local eye care schemes in Wessex by adapting the Local Optical Committee Support Unit's (LOCSU) community pathway for people with learning disabilities

To gain further perspectives into this important aspect of healthcare, we also recommend additional research into experiences of sight tests with the following groups: children with learning disabilities and/or autism, people with more severe and profound and multiple learning disabilities (PLMD) and/or severe autism, their carers and support workers, and eye care professionals.

# Introduction

In late 2019, [Wessex Voices](https://www.wessexvoices.org)<sup>2</sup> was asked by NHS England Wessex (South) to engage with adults with learning disabilities and/or autism to understand their experiences of and barriers to sight tests and the associated aftercare. We have worked on this project with the Wessex Local Eye Health Network (LEHN) within the NHS, which focusses on eye health issues across Dorset, Hampshire and the Isle of Wight, and SeeAbility, a national charity that supports and advocates good eye care for people with learning disabilities.

This report provides background on the current context of eye health and sight tests for adults with learning disabilities and/or autism nationally and across Wessex; an overview of survey respondents broken down into geographical area, age and gender; and key themes and recommendations based on our findings. Throughout this report, feedback from carers we spoke with has been included because of their particular role in supporting people with learning disabilities and/or autism to access eye care services.

The findings and recommendations will be used to inform the NHS on how the quality of eye care can be improved, and whether a locally or nationally commissioned pathway for eye care for adults with learning disabilities and/or autism is needed in England. Commissioning specialised care for people with learning disabilities already exist, such as for NHS dental services and a national scheme for GPs to offer them annual health checks.<sup>3</sup> Our findings and recommendations may also help health colleagues to meet their Equality Act 2010<sup>4</sup> duties by ensuring they make reasonable adjustments and provide accessible information as outlined in the NHS Accessible Information Standard.<sup>5</sup>

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<sup>2</sup> <https://www.wessexvoices.org>

<sup>3</sup> For example see <https://www.england.nhs.uk/commissioning/wp-content/uploads/sites/12/2015/09/guid-comms-specl-care-dentstry.pdf> and <https://www.england.nhs.uk/learning-disabilities/improving-health/annual-health-checks/>

<sup>4</sup> [http://www.legislation.gov.uk/ukpga/2010/15/pdfs/ukpga\\_20100015\\_en.pdf](http://www.legislation.gov.uk/ukpga/2010/15/pdfs/ukpga_20100015_en.pdf)

<sup>5</sup> <https://www.england.nhs.uk/ourwork/accessibleinfo/>

# Background

Existing national data indicates there is an estimated one million adults with learning disabilities and approximately 458,000 autistic adults living in England. Across Wessex (i.e. Dorset, Hampshire, Isle of Wight, Portsmouth and Southampton), there are an estimated 62,630 adults with learning disabilities<sup>6</sup> and over 15,000 autistic adults.<sup>7</sup> This report looks specifically at adults with learning disabilities and/or autism, as the conditions are often co-occurring with approximately 20-30% of people with a learning disability also having autism across the country.<sup>8</sup>

Adults with learning disabilities are much more likely to have sight issues with six out of ten likely to need prescribed spectacles more than other people.<sup>9</sup> They are also 10 times more likely to have a serious sight issue.<sup>10</sup> On the other hand, it is unclear how many autistic adults have visual impairments, but there is increasing evidence that autistic adults are likely to have a sight condition. More research is needed on this subject. It can be inferred that should someone have both autism and a learning disability, their likelihood of having a sight issue increases.

The more severe or complex a person's learning disability is, the more serious their sight issue is likely to be. According to Public Health England's recent report on eye care for people with learning disabilities, "Specific conditions such as Down's syndrome and cerebral palsy can increase the risk of sight problems and there is increasing evidence that autism is associated with poorer sight."<sup>11</sup> For those with profound and multiple learning disabilities (PLMD), visual impairment is

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<sup>6</sup> <https://www.england.nhs.uk/south/wp-content/uploads/sites/6/2019/02/wessex-eye-health-needs-assessment-2018.pdf>

<sup>7</sup> Taken from a range of sources, including local autism strategies and 2018 mid-year population statistics.

<sup>8</sup> <https://www.england.nhs.uk/wp-content/uploads/2020/01/Learning-disability-and-autism.pdf>

<sup>9</sup> <https://www.rnib.org.uk/sites/default/files/Emerson%20report.pdf>

<sup>10</sup> <https://www.seeability.org/Handlers/Download.ashx?IDMF=316cd01e-01c4-452c-8951-b16a87a0674f>

<sup>11</sup> <https://www.gov.uk/government/publications/eye-care-and-people-with-learning-disabilities/eye-care-and-people-with-learning-disabilities-making-reasonable-adjustments>

likely to be a significant problem, with some reports recommending that adults with PMLD should be considered visually impaired unless proven otherwise.<sup>12</sup>

Good eyesight contributes to a person's quality of life and enables people to carry out everyday activities and participate in society more easily. Attending regular sight tests can help people diagnose sight conditions or impairments sooner and prevent sight loss. Undiagnosed sight conditions or impairments are not always noticeable to the person as some sight conditions can remain asymptomatic for a long time, such as cataracts. People may still be able to perform daily activities while these conditions develop gradually, but they risk having partial or full sight loss and become more prone to accidents like tripping or falling. Age is also a factor that can influence sight quality. Most eye diseases are age related and the need for spectacles, particularly for near visual tasks, increases from the age of 40 years onwards so it becomes increasingly important for people to have their eyes checked regularly.

The lack of national and local data on eye health and experiences of sight tests for adults with learning disabilities and/or autism makes it hard to discern exactly how many people are or aren't attending sight tests, and which eye conditions they may have. Despite this, efforts are being made to improve access to eye care services for people with learning disabilities and/or autism in pockets in parts of the United Kingdom. This includes six local eye care pathways established in areas such as Greater Manchester, London Boroughs of Sutton and Cheshire and Merseyside, where enhanced fees and training for optometrists is offered (thus enabling people with learning disabilities to be signposted to these pathways). In 2018, a national scheme was established in Scotland to enable all optometrists to claim an additional fee for seeing patients with complex needs, reflecting the time the person might need when visiting an optical practice. Currently there is no similar eye care pathway across Wessex. Though this report focusses on the adult population, it is worth mentioning for children with learning disabilities, there is a

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<sup>12</sup> <https://www.gov.uk/government/publications/eye-care-and-people-with-learning-disabilities/eye-care-and-people-with-learning-disabilities-making-reasonable-adjustments>

national programme in England that aims to improve eye care for children in special schools.<sup>13</sup>

### Examples of Eye Care Schemes

Six known local eye care schemes or pathways exist in England. A full list can be found here on SeeAbility's website: [www.seeability.org/pathways](http://www.seeability.org/pathways)

Scotland's scheme where optical practices get an additional payment for seeing patients who have complex needs can be found here:

[www.sehd.scot.nhs.uk/pca/PCA2018\(O\)02.pdf](http://www.sehd.scot.nhs.uk/pca/PCA2018(O)02.pdf)

## Methodology

We undertook a review of existing literature to understand the experiences of adults with learning disabilities and the associated uptake locally and nationally. Of particular interest were the findings that recognised the additional time needed for sight tests and the subsequent scheme that was established in Scotland in 2018.

Our main tool to gather feedback was a survey that was developed in collaboration with the Wessex Local Eye Health Network (LEHN) and SeeAbility. Questions from our survey were designed in a way to understand:

- What barriers might have prevented someone from going for a sight test, especially if they had never been to one before or hadn't attended a sight test in a long time
- For those who attended a sight test, what their experiences were throughout the process (e.g. booking an appointment, at the sight test, choosing and fitting glasses, post-appointment glasses and eye care)

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<sup>13</sup> <https://www.longtermplan.nhs.uk/>

Questions were tested with both people and carers in Dorset and Hampshire. Their feedback helped to refine the questions and response options, so they were closer aligned with what people were interested in feeding back. The final version was then adapted into Easy Read.

The survey went live from December 2019 to February 2020 and was available in several formats:

- An online version using Smart Survey
- Easy Read version that could be printed from the Wessex Voices' website
- 200+ hard copies in Easy Read were printed and mailed with freepost envelopes to various voluntary sector and day services/centres
- Group interviews were conducted across Dorset, Hampshire and the Isle of Wight
- Phone interviews and individual interviews were also offered on our website and in meetings, in case this was of interest

Group interviews were semi-structured with key questions prompting initial discussion. More straightforward questions eliciting yes/no responses helped to initiate conversations (e.g. "Have you ever had an eye test?"), which helped to deepen the feedback as people began to share experiences more freely.

All participation, responses and feedback were anonymous and voluntary, and this was explained to people before they took part.

## Who We Heard From

A total of 120 people participated in our project, either by completing an online survey (19 people/16% of total participants), a hard copy survey (48 people/40%) or participating in a group interview (53 people/44%). The total number of

participants is comprised of adults with learning disabilities and/or autism, as well as carers who completed the online or hard copy survey on the behalf of someone with a learning disability and/or autism.

The majority of people who responded live in Hampshire (68%), particularly in or in surrounding areas of Southampton and Portsmouth. 15% of people live in Dorset, 5% on the Isle of Wight and 12% chose not to share their location.

Half of people said they are male (50%) with a little over a third who said female (34%). 5% preferred to use another term to describe themselves, most noting 'non-binary' or a similar description, and 12% chose not to disclose their gender.

Most people fell into either the 18 to 34 age range (41%) or 35 to 54 years (46%). There were smaller numbers of people who were aged 55 to 74 years (5%) or who happened to be under 18 (2%). We were not able to speak with people aged 75 years or over and the remaining 7% of people chose not to share their age.

The majority of people we heard from either had one or a combination of the following: autism and/or mild or moderate learning disabilities.

For more information on who participated in our survey, please see Appendix A.

## Findings

The findings below provide an overview of the key themes drawn out from our data. While the findings primarily focus on adults with learning disabilities and/or autism, feedback we received from carers has also been included where relevant as many people told us carers are integral for them to access sight tests. Ensuring carers and support workers are also properly supported means everyone involved will have a better experience. The statistics presented in the sections below reflect the responses we received from group interviews, the online and hard copy versions of the survey.

## Are people going for sight tests?

### Key points

Most people who participated in the survey, either online, hard copy or group interviews, had been to a sight test in the past (87%), and smaller numbers stated they had not (13%) or chose not to disclose this (1%).

However, when we look at how often people go for a sight test, while most said they had been to one in the last 2 years (44%), a significant portion of people said they could not remember when they last went (34%), which was also common in group interviews. Other people had been to one more than 2 years ago (11%), more than 5 years ago (9%) or chose not to answer (2%), which concur with results from other reports we found. They highlight that around half of people with a learning disability do not appear to be going for sight tests in the recommended period (i.e. every 2 years for adults.)<sup>14</sup>

Whether people choose to go for a sight test or not is affected by many factors, of which the ones below stood out the most and each is discussed in more detail in the remainder of this report:

- Having the support to facilitate appointments, including prompting, booking and transport
- Understanding what happens at sight tests and knowing what will happen before the appointment
- Easy access to sight tests, including access to having sight tests at home
- Optometrists and their staff being patient and giving people enough time for the test and when choosing and fitting spectacles. Seeing the same optometrist and staff at every appointment was also very helpful for people
- The priority of cost for people with learning disabilities and/or autism

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<sup>14</sup> <https://www.seeability.org/Handlers/Download.ashx?IDMF=316cd01e-01c4-452c-8951-b16a87a0674f>

- Fittings and use of glasses and/or contact lenses, as well as any problems with their glasses
- Having general information about sight tests and good eye care. The more aware people were about what sight tests could do and general eye health, the more likely they were to prioritise and attend sight tests
- Concerns about administrative and communication processes, particularly bookings

When people were asked if they had requested additional support when booking their sight test appointment, 33% of people said they had. When asked later in the survey if they received the support they requested at the time they had booked their appointment, 14% of people said they did. One person noted their parent, who had booked the appointment for them, had informed the optometrist that their child could not speak or read. The optometrist was able to support by showing “projections of aeroplanes, butterflies and rabbits.”

It is possible that 14% is an underestimation of the support people received, as many people did not book their own sight tests and were assisted by a carer. Additionally, due to how the questions and responses were structured in this survey, we can elicit that people were given requested support, such as additional time and patience.

Prioritisation of eye health can also affect whether people attend sight tests or not. Feedback on this was varied. For many people there is a lack of understanding about sight tests and what sight tests can do. In group interviews, several people said their eyesight was fine so didn't think they needed to attend one, but they were also not aware that sight tests can detect certain conditions or diseases before they become symptomatic. However, for those who were diagnosed with an eye condition at a young age and/or prescribed spectacles, eye health is generally quite important and most people attend sight tests regularly. For those who need regular check-ups at a hospital, they said in group interviews that they went for

sight tests at both the hospital and at a local optometrist and seemed to understand why they needed to attend both.

Carers, particularly parents or other family members acting as carers, sometimes have limited capacity to provide the support required. This can influence the prioritisation of sight tests amongst other competing demands. One parent carer noted the main barrier to them facilitating sight tests was because they had “too much already on my plate and keep forgetting” in “supporting my autistic children.”

### **People Who Have Never Attended a Sight Test**

15 out of the 120 people (13%) we spoke to said they had not been to a sight test before. When asked what had stopped them from going for a sight test in the past, most people (33%) said they did not know, 17% said they needed more support to attend a sight test. The remaining responses were equally split with people saying they did not know where to go, found it difficult to get to an optometrist, were worried about the costs involved and/or could not read. Comments we received about barriers to accessing sight tests included:

“Wouldn't cope with going to an optician's needs a home visit”

“Too much already on my plate and keep forgetting”

Two people noted sight tests were not a priority for them and felt they could see well enough. One person said they feared being teased by others if they were prescribed glasses. Both were not aware that eye conditions or diseases could be detected through sight tests.

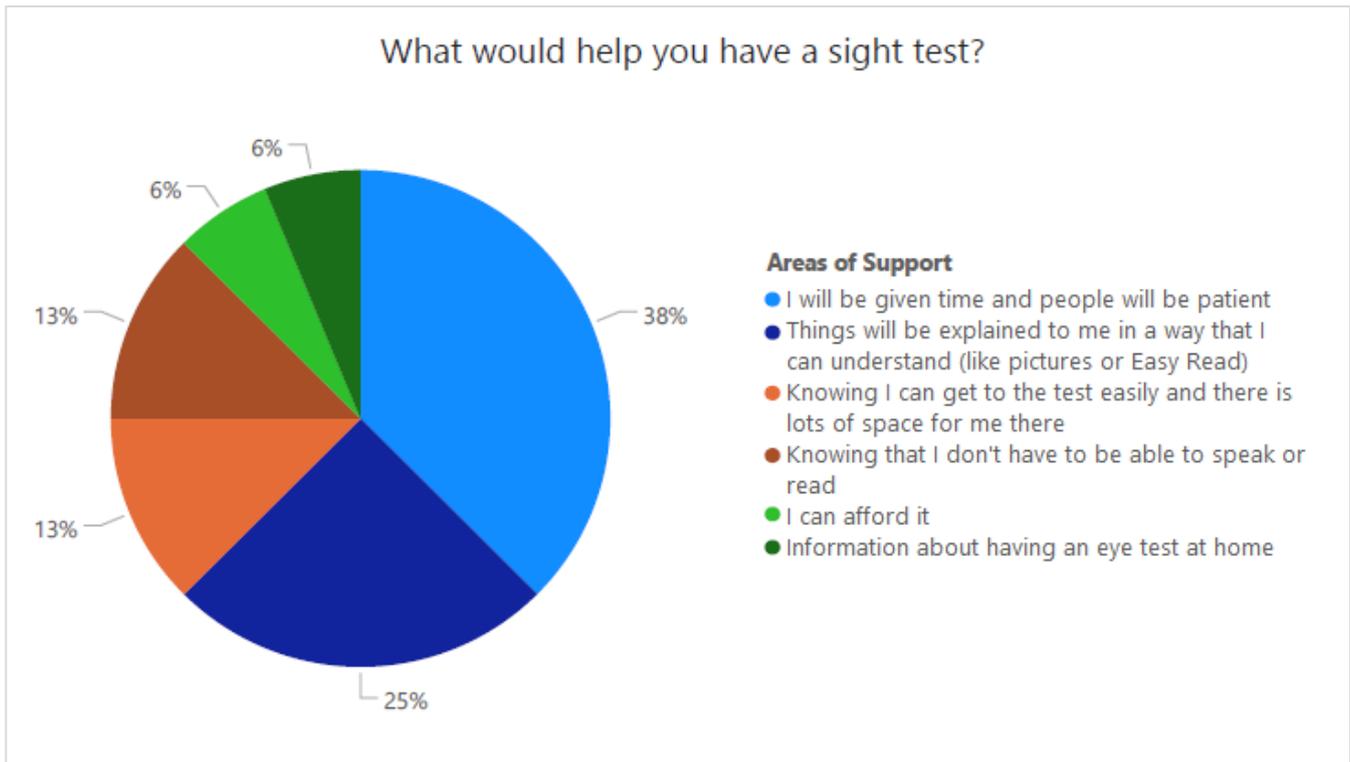


When the same group of people were asked what would help them go for a sight test, most people (38%) said being given time and people being patient would be helpful, followed by having things explained to them in a way they could understand, such as using pictures or Easy Read (25%). Other areas of support that would help them go for a sight test are: knowing they can get to the test easily and there is a lot of space for them there (13%), knowing they do not have to be able to speak or read (13%), knowing they can afford it (6%) and having information about having a sight test at home (6%).

Everyone who answered this question shared additional feedback on what would help them go for a sight test, particularly in group interviews:

- Many wanted more information about sight tests and good eye care, including what happens during a sight test before people attend.
- An autistic adult said having a separate quiet room or waiting room would be helpful and more comfortable (this was also highlighted in group interviews by several adults with learning disabilities and/or autism and carers who had been to a sight test before.)

- Two autistic adults noted they would like more personal space during the test. They felt optometrists were too close to them during appointments.
- One person said that they would find it helpful to look at the equipment that would be used at a sight test before the appointment, which they had access to at a recent diabetic eye screening appointment.



## Having support to facilitate appointments

### Key Points

People told us having support was the most important aspect, particularly having support from a carer or support worker to help them attend sight tests (42%). How much support and what type of support is needed varies person by person, as there are some individuals with milder learning disabilities and/or autism who do book and attend their own appointments. However, support is generally needed for one or more of the following:

- Book appointments

- Escort people to appointments (for sight tests and/or glasses fittings)
- Support communication between people and all staff involved (sometimes this may include advocating for support needed)
- Pay for appointments and/or prescribed glasses. This applies to both the person with a learning disability who may need support to pay and for parent carers, who may cover any costs themselves
- Support for broader mental health issues if needed, as this can affect prioritisation of health issues more broadly, including eyes. Two people we interviewed said their diagnosed depression and/or anxiety was a significant barrier to them booking sight tests and they would find it very helpful for a carer or support worker to book and take them to the appointment

The above points were noted in some of the feedback we received by people:

“I can only get to an appointment if one of my parents can arrange it and take me.”

“Thankfully my parents help book, pay for and arrange my transport to eye tests and dentists. Otherwise I would not manage to go. They also arrange my children’s appointments. I live ‘independently’ so would not be expected to have this need by social services.”

“Someone else phoning to book an appointment (or transport to the receptionist to book it face to face). I can’t use a phone call. I can’t understand people at all. Then I need help getting there and back with my kids.”

From a carers’ perspective, people told us having appointment or reminder letters in Easy Read or in a larger font size would help ensure appointments or important information is not missed, as required under the NHS Accessible Information Standard. A few carers noted that the font size is too small on current letters and

if the service user it is addressed to is visually impaired or is not able to read, then the information risks not being read at all and being discarded. Phone calls or texts were recommended alternative ways of communicating, depending on the person's communication needs.

## Understanding what happens at sight tests

### Key Points

Ensuring both people and their carers or support workers understand what exactly happens during a sight test and what costs are involved, would help people feel prepared for sight tests and may influence their inclination to go. When asked what would help people to go for a sight test, the second most popular feedback was for things to be explained to people in a way that they could understand, such as using pictures or Easy Read forms (25%). Some people and carers said the following about having information on sight tests beforehand:

“Information before we go about what happens”

“All the steps involved in the test will be explained to me beforehand. Maybe with accompanying pictures”

“They could send a letter with pictures as I find it hard to read”

“It was fine. The optician showed projections of aeroplanes, butterflies and rabbits. I signed which I could see”

One person noted that for their diabetic eye screening, they were able to visit the location in advance of where the appointment was taking place, which they found helpful:

“Diabetic eye screening let me go and talk to them and look at the equipment they would use before my appointment”

In group interviews, when asked if their optometrists used Easy Read information during tests or to share sight test results, many people said this did not happen and were not aware this was possible. Similarly, carers we spoke to reported the same findings and highlighted concerns about the quality of sight tests and how optometrists arrived at diagnoses, particularly if communication between people and the optometrist was not particularly clear or effective.

It may be likely that some optometrists are not aware of existing Easy Read forms/templates to explain results or when to use them. National templates do not exist and SeeAbility is the only provider we found of these forms. When Easy Read forms are used, they may help improve communication between people, carers, optometrists and optical staff, particularly when explaining the results of a sight test. These forms would also support optometrists and their staff meet the NHS Accessible Information Standard. One service user in a group interview noted, “It would be helpful to have an Easy Read form with your name, address and information about your results.” Likewise, these forms can also be used by individuals and carers to ensure they know what to ask, like additional support when booking an appointment, or when wanting more information about the results of a sight test.

Another person suggested having a “Yellow Health Book”<sup>15</sup> or health passport specifically for eyes that was available in both electronic and paper format. This is so optometrists, dispensing opticians, ophthalmologists, general practitioners and other health professionals could access sight information on individuals, making eye checks an easier process for people, particularly if they require treatment.

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[http://www.poolefamilyinformationdirectory.com/mediamanager/poole/fis/files/yellow\\_book\\_poster.pdf](http://www.poolefamilyinformationdirectory.com/mediamanager/poole/fis/files/yellow_book_poster.pdf)

## Accessible and Easy Read Information

The NHS Accessible Information Standard outlines the ways in which health and social care information should be made available for patients and the public who may have a disability, impairment or sensory loss and who may need information communicated in a different format. Organisations that provide NHS services or publicly funded adult social care are legally required to comply with the standard. For more information, you can read about the standard on the NHS website: [www.england.nhs.uk/ourwork/accessibleinfo](http://www.england.nhs.uk/ourwork/accessibleinfo)

SeeAbility currently offer free Easy Read templates that can be downloaded for sight test appointments. These can be used by anyone, including adults with learning disabilities and/or autism, carers, optometrists and their staff, to book appointments, understand test results and more:

[www.seeability.org/eye-care-factsheets](http://www.seeability.org/eye-care-factsheets)

The National Autistic Society also has guidance and resources available on their website to support autistic adults going for a sight test:

- For autistic adults and carers:  
[www.autism.org.uk/about/health/eyecare.aspx](http://www.autism.org.uk/about/health/eyecare.aspx)
- For optometrists, their staff and other eye care professionals:  
[www.autism.org.uk/professionals/health-workers/eyecare.aspx](http://www.autism.org.uk/professionals/health-workers/eyecare.aspx)

## Easy access to sight tests (including tests at home)

### Key Points

Easy access can mean different things to different people. For some, they highlighted it meant finding a learning disability friendly or recommended optometrist; some said having an optometrist close to where they live and/or accessible building; and for others, it means knowing more about different locations sight tests can take place at, particularly at home.

## Sight tests at home

To understand how people felt about the location of sight tests, including those who had never attended a sight test before, we asked them where they were having their sight tests and where they would prefer to have them. In the graph below, we can compare where people are currently going versus where they would prefer to go, noting:

- Most people said they attend sight tests at a local optometrist or an independent optometrist (78%) and many are comfortable continuing to see their local optometrist (68%).
- Generally, people who go to a hospital for a sight test, including those who also go to their local optometrist on a regular basis, have reported positive experiences when they go for a sight test.
- There are slightly higher figures for preferred alternative locations, such as having tests at home, at a day centre or at their local GP. Feedback we received from people noted these were comfortable and familiar places, which emphasises the need for people to feel comfortable and the importance of being familiar with staff to ensure people have a good experience and are likely to attend future appointments.
- There is a smaller number of people (17% of total participants), including carers, who would prefer for sight tests to be done at home, primarily for ease and comfort. Some people have more moderate or complex learning disabilities and/or physical disabilities that limit their ability to attend a sight test outside of their home. While this is a smaller number, for the people who this affects, this is an important service for them to have access to, with feedback stating:

“My son would feel safe in his home environment.”

“At home so that my parents don't have to take me to the venue.  
My mum doesn't drive so it's very difficult for her to take me  
there.”

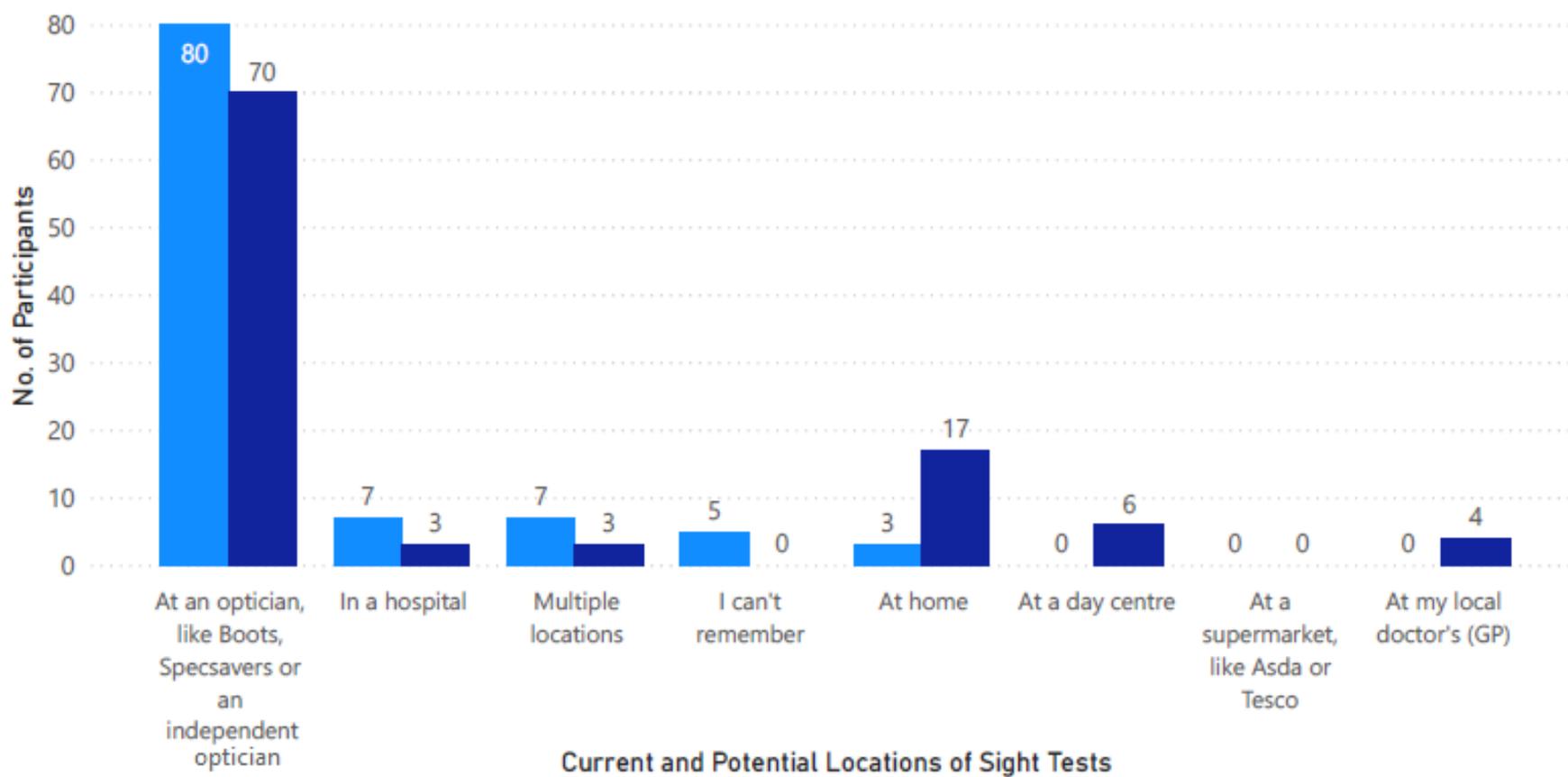
“Wouldn't cope with going to an optician's needs a home visit”

“People come to the house to check [service user's name] eyes.”

- When we looked at the breakdown of responses from people who had never been for a sight test before (13% of total participants), we found that while quite a few people would also prefer to see a local optometrist (30%), higher numbers of people would prefer to have a sight test at home (30%), at a day centre (20%) and/or at their local GP surgery (20%). A little over half of people who answered this question said this was largely due to comfort and familiarity of staff and the building where the sight test took place.

## Location of Last Sight Test vs. Preferred Location

Key: ● Last Sight Test ● Preferred Location



## Having enough time and patient optometrists and staff

### Key Points

People told us, particularly in group interviews, that having enough time and having patient optometrists and staff were two big factors that supported them having a good experience at a sight test. If people felt they had enough time to do the sight test and to select and fit spectacles, and staff were friendly and patient with them, this would help people feel they had a good experience and they would be more inclined to go for their next appointment. Sometimes this may require staff to deal with behaviours they do not usually see from other customers, as one carer noted it is helpful to have staff that “...understand children with additional needs, and remain calm when they get distressed” and another noting having, “Trained staff to support my anxieties” would help them during sight tests.

For those who have had positive experiences, they reported:

“The people who work there are really good with young adults who have learning disabilities”

“Because they are very kind people and I trust them”

“Helpful staff and friendly”

“Because that's where I've always gone”

“It was fine. My dad told them I cannot speak or read. They said they had an optician who would cope.”

### Familiarity

Often times when people noted having enough time for sight tests and dealing with patient and friendly staff, the topic of familiarity with optical staff and the premises would also come up. As mentioned earlier, if people feel they have had a

positive experience, they are more likely to attend future sight tests, particularly with the same optometrist. Comments we received for reasons why people would like to continue seeing their current optometrist, regardless of where they are based included:

“It's a place I have been before”

“Easy to go to and familiar environment”

“Where I've been before”

“Familiar surroundings”

### **What does good practice mean?**

When people spoke of good practice with sight tests, it meant having a positive and easy experience. A list of recommended optometrists in Dorset, Hampshire and the Isle of Wight where people and carers had had a good experience can be found in Appendix B.

### **Is cost a concern?**

Currently there is an NHS contract to deliver sight tests, which attracts a generic fee of £21.31 for all patients to be seen under the NHS. For people on certain benefits, they may be eligible for an NHS paid for sight test.<sup>16</sup> In other reports we found, cost was a significant concern for many people and is a common barrier that deters people from attending a sight test. Interestingly, this was a concern for people we heard from but not as large of a concern as we anticipated. We suspect this is because carers are more likely to be the ones dealing with cost and may expect this to be a cost they need to pick up. This needs further exploration to understand how cost may or may not prevent someone from attending a sight test

<sup>16</sup> <https://www.nhs.uk/using-the-nhs/help-with-health-costs/free-nhs-eye-tests-and-optical-vouchers/>

across Wessex. Considering that adults with learning disabilities and/or autism are a high-risk group and regularly experience health inequalities, it is important for this barrier to be removed. Many optometrists also offer free sight tests, which may have influenced the results we received.

Below are the responses we received regarding cost when asked the following questions:

- When asked, “Has anything ever stopped you from going for an eye test?” Seven out of 120 people said they were “worried about what it would cost.”
- 20 out of 120 people said knowing they could afford the sight test would help them have a sight test.
- When asked what happened at their last sight test, 21 out of 120 people said the optometrist had affordable glasses or contact lenses.
- One person noted glasses were expensive, saying they were, “making do as really need another test but can’t afford it.” Similar comments regarding the cost of glasses were made by several people at different group interviews, though some people were aware of NHS optical vouchers.<sup>17</sup>

## **Fittings and use of glasses and/or contact lenses**

Comfortable glasses and/or contact lenses can influence whether or not someone uses them consistently and gets the most out of their eyesight. Out of the 120 people we heard from, 61 people indicated they wear glasses.

Most people who were prescribed glasses felt they were fitted comfortably (42%), with only 8% of people stating they were not fitted comfortably. A significant portion of people did not disclose whether this was comfortable or not (39%) and a much smaller portion said they did not need glasses or contact lenses (11%). No one mentioned they wore contact lenses, but one autistic adult said it would be

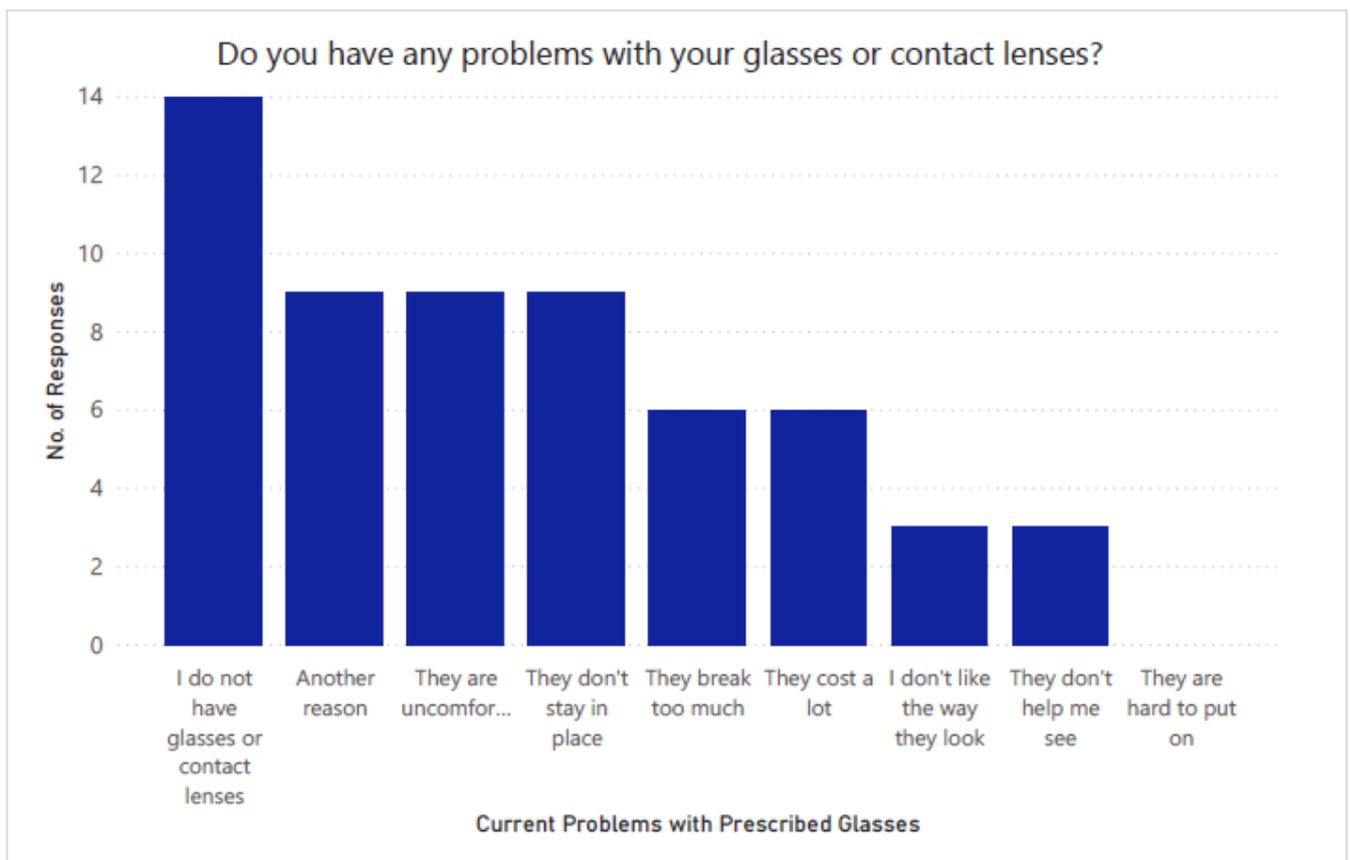
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<sup>17</sup> <https://www.nhs.uk/using-the-nhs/help-with-health-costs/free-nhs-eye-tests-and-optical-vouchers/>

helpful for them to have a pair. Another adult with a milder learning disability said he would likely wear contact lenses, had he not been diagnosed with keratoconus, which is when the cornea thins progressively and becomes a cone-like bulge.

Of those who were prescribed glasses, 59% said they wear their glasses when they were meant to, 15% said they did not and 26% did not disclose this.

In terms of any problems people might have with their glasses, the issues are varied, with most people reporting their glasses are uncomfortable and/or do not stay in place. Please note, for the question in the graph below, people were able to select multiple options in the survey and some chose not to answer this question.



Alongside the response option, “Another reason”, people said they were experiencing the following issues:

- “Although prescribed, she would not wear them.”
- “I don’t always remember to have them”
- Two people noted in group interviews that they felt they might need to get their glasses checked to ensure the lens prescription was correct.
- One person noted in group interviews that he needed to get his glasses resized. After losing weight, he found his glasses did not fit his head as well as they did before.

## General information about sight tests and good eye care

### Key Points

In addition to having more information about sight tests, many people wanted information about good eye care, where to find learning disability friendly or recommended optometrists and NHS paid for sight tests and discounts on prescribed spectacles. Two people noted their experiences:

“I used to trust an independent optician, but they sold to a large chain company. So now I don’t know where to go next. I don’t know where I will go next”

“I don’t know whether to go to my GP or just to a shop on the high street and will it cost me for the test”

Some people in group interviews, including carers, did not know that sight tests detected more than just whether someone needed glasses or not. Some were not aware that eye conditions and sight issues were more common in individuals with learning disabilities and that sight conditions, such as blindness, could affect younger people and not just elderly individuals.

One group of carers we spoke with in Dorset said they did not know where to go for information, with one carer noting their GP was unable to recommend a learning

disability friendly optometrist. People told us having an easy to access website would be helpful.

The topic of Annual Health Checks<sup>18</sup> came up consistently in group interviews and when asked if their GP had asked about their eyes at their last annual health check, most people said this did not happen and only a few said they had been asked about this. One carer noted in the online survey:

“As she gets older, I feel it is important to test the health of her eyes on a regular basis. This is something not covered under the LD [learning disability] Annual Health Check.”

Anyone with a learning disability over the age of 14 can get an annual health check. GPs are incentivised to perform annual health checks but there is concern not all adults with learning disabilities are attending them as uptake is just over 50%. Considering this service looks at a broad range of health issues on a consistent basis, this would be a useful starting point to check the health of people’s sight and ensure these checks are being done consistently. Many carers we spoke with said this would be useful for them, particularly as they have multiple priorities to manage regarding the people they care for.

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<sup>18</sup> <https://www.england.nhs.uk/learning-disabilities/improving-health/annual-health-checks/>

## Places for general information, including learning disability and/or autism friendly optometrists

Carers we met with on the Isle of Wight recommended their Special Education Needs and Disability Local Offer as one of their preferred websites to house information and resources: [www.iow.gov.uk/localoffer](http://www.iow.gov.uk/localoffer)

Existing resources can be found on the following websites:

- SeeAbility has an online database of learning disability friendly optometrists: [www.seeability.org/find-an-optometrist](http://www.seeability.org/find-an-optometrist)
- The National Autistic Society also has a few optometrists on their website who they have awarded the Autism Friendly Award, an award for businesses who the National Autistic Society have worked with to create more autism friendly buildings and facilities:  
[www.autism.org.uk/professionals/autism-friendly-award/holders.aspx](http://www.autism.org.uk/professionals/autism-friendly-award/holders.aspx)

## Concerns about administrative and communication processes

Some carers had supported someone going for a sight test at a hospital and generally reported the treatment and service received as good or excellent, but there were some concerns around the administrative process. One carer noted that their spouse required further sight testing after having initial tests at a hospital, but due to a breakdown communication between the hospital and the GP surgery, it took another four years until they received the results from a new GP. The experience has resulted in their spouse's sight issues having progressed further than they might have, had they received treatment sooner.

Several carers noted that when people were sent letters, sometimes carers were not made aware. This meant if the person they cared for could not read it or did not understand it, the letter risked being discarded and forgotten. If

communications are addressed to the carer as well, provided the person consents to this, then carers can also support with ensuring people continue to access health services, including sight tests, when they need to.

## Recommendations

Everyone should have access to good eye care, and no one is too disabled to have a sight test. Based on our findings, our recommendations to improve access to sight tests and good eye care for adults with learning disabilities and/or autism are (please note, these are listed in no particular order):

### **1. Increase general awareness of sight tests and good eye care through a multi-pronged approach. Recommended minimum approaches are:**

- Promote existing resources of learning disability and/or autism friendly optometrists, such as SeeAbility's optometrist database, on a regular basis through various channels, such as learning disability partnership boards and autism forums.
- Co-produce or co-create regular public health campaigns with adults with learning disabilities and/or autism and their carers or supporters to promote the importance and benefits of good eye care, as well as resources, like Easy Read Sight Test forms.
- Work with Local Optical Committees and members of voluntary, community and social enterprises (VCSE) to hold information sessions or workshops for both people and for carers (including tools and resources, such as Easy Read forms that can be used at tests).
- Offer sight tests at alternative locations throughout the year, such as day centres, residential care services or other community venues that

people can drop into or sign up to ahead of time. These could potentially be combined with information sessions or workshops and could be supported by Learning Disability Nurses. This will require reviewing the existing NHS contract to ensure it has the flexibility to facilitate this to happen.

- 2. Ensure optometrists and optical staff are better supported and able to communicate and support others by completing learning disability and autism awareness training and ensuring reasonable adjustment flags are used on patient records.** We understand that this recommendation should support future work around mandatory awareness training for NHS staff and NHS Digital's rollout of a reasonable adjustment flag for patient records.<sup>19</sup> It is important for optical practices to be linked in with NHS digital systems to ensure patient records transfer across systems seamlessly and provide the excellent patient experience.
  - Until optical practices are linked in with NHS digital systems and where possible, optical practices should flag people's access needs within their own databases and encourage people to let them know if they have any support needs for their appointments.
- 3. Ask the Local Optical Committees (LOC) and Local Medical Councils (LMC) in Dorset and Hampshire to review how Annual Health Checks can be improved to ensure GPs ask about a person's eye sight and prompt them for sight tests if needed, and how Annual Health Checks can be used to collect and contribute to national data on sight tests and eye conditions for adults with learning disabilities and/or autism.**
- 4. Co-create a learning disability and autism friendly optometrist standard with people and carers, and commission local learning disability and**

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<sup>19</sup> <https://digital.nhs.uk/services/reasonable-adjustment-flag>

autism user-led organisations to undertake quality checks of this standard to ensure they are being met.

- Provide a list of learning disability and/or autism recommended optometrists who meet this standard to the NHS website. Adding in the function to share reviews and ratings would be a helpful option according to people we spoke to.

5. Use the findings of this report to support the call for more dedicated eye care schemes for adults with learning disabilities and/or autism – ideally nationally, but in the absence of this, create a local eye care scheme in Wessex. National and local eye care schemes should adapt the Local Optical Community Support Unit’s (LOCSU) community pathway<sup>20</sup> for sight tests for adults with learning disabilities and/or autism and learn from existing pathways in England and Scotland. These pathways recognise the need for additional fees that recompense and incentivise targeted eye care in community settings. Additionally, further research is recommended on experiences of sight tests for children with learning disabilities and/or autism, people with profound and multiple learning disabilities (PLMD) and/or severe autism, and a review with their carers, support workers and eye care professionals to understand their perspectives on these challenges. Considering the limitations on time and funding for this piece of engagement work, further research would greatly benefit the development of eye care schemes, to ensure appropriate support is provided for all involved.

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<sup>20</sup> <https://www.locsu.co.uk/commissioning/pathways/learning-disabilities/>

# Conclusion

Everyone has the right to access the health services they need, including people with learning disabilities and/or autism. Public sector organisations and those delivering NHS services have a legal obligation to ensure they make reasonable adjustments to facilitate this.

It was positive to hear of the good experiences people have had, where they felt supported by their local optometrist and their staff. Several people we spoke with felt they had excellent support and were happy to continue attending future sight tests. However, people also shared the barriers and poor experiences of sight tests, which are consistent with those in other external reports, such as SeeAbility's 2016 report, "Delivering an equal right to sight," and Public Health England's 2020 report, "Eye care and people with learning disabilities: making reasonable adjustments."

While the establishment of a national pathway in England, particularly for those with more complex needs, would greatly enhance people's health and wellbeing, there are other improvements that can be made sooner that would also support awareness of good eye care.

People who have regular, positive experiences during sight tests and understand the importance of good eye care are likely to keep attending future appointments and are likely to keep seeing the same optometrist. Making it easier for adults with learning disabilities and/or autism and their carers to access eye care, taking into consideration how complex or busy people's lives can be, will help improve people's quality of life.

# Appendix A: Who We Heard From – Ethnicity & Learning Disability

In terms of ethnicity, people who participated described themselves as White (88%), Asian or Asian British (5%) or Mixed (3%). 4% chose not to disclose their ethnic background and no respondents described themselves as Black or Black British.

When asked about their learning disability and/or autism, 47% said they had autism, Asperger's or were on the autistic spectrum, 44% said they had another type of learning disability, 8% said they had down's syndrome and 1% specifically mentioned having a mild learning disability and being on the autistic spectrum.

For those who said they had another type of learning disability, comments included:

- Mild, severe or complex learning disability noted by several people
- Learning difficulties (mentioned a few times)
- Cerebral palsy
- Speech and language disorders or difficulties
- Mental health
- "I have got William's Syndrome"
- "I do not speak or read"
- "Development delay, sensory issues and my son suffers from developmental trauma from first three years of abuse prior to me adopting my son"
- "I am undiagnosed"

# Appendix B: Recommended Optometrists and Hospitals

Several optometrists and hospitals were recommended to us by people who participated in the survey, who told us the optometrists and hospitals listed below provided good or excellent quality sight tests and experiences for people with learning disabilities and/or autism. This list is not a definitive list and does not necessarily define best practice:

## Dorset, including Bournemouth, Christchurch and Poole

- Specsavers, Bournemouth ([www.specsavers.co.uk/stores/bournemouth](http://www.specsavers.co.uk/stores/bournemouth))
- Vision Express at Dolphin Shopping Centre, Poole ([www.visionexpress.com/opticians/poole/poole](http://www.visionexpress.com/opticians/poole/poole))
- Julian May, Southbourne ([www.julianmayopticians.co.uk](http://www.julianmayopticians.co.uk))
- Boots, Winton, Bournemouth ([www.boots.com/stores/3249-bournemouth-winton-opticians-bh9-2ad](http://www.boots.com/stores/3249-bournemouth-winton-opticians-bh9-2ad))
- Andrew Care Opticians, Dorchester ([www.andrewcareopticians.co.uk](http://www.andrewcareopticians.co.uk))
- Boots, Dorchester ([www.boots.com/stores/3958-dorchester-cornhill-opticians-dt1-1bq](http://www.boots.com/stores/3958-dorchester-cornhill-opticians-dt1-1bq))

## Hampshire, including Southampton and Portsmouth

- Boots, Romsey ([www.boots.com/stores/1019-romsey-the-hundred-so51-8gd](http://www.boots.com/stores/1019-romsey-the-hundred-so51-8gd))
- Leightons on the Avenue, Southampton ([www.leightons.co.uk/branches/southampton](http://www.leightons.co.uk/branches/southampton))
- Sefton Eyecare, Woolston ([www.nhs.uk/Services/opticians/Overview/DefaultView.aspx?id=19232](http://www.nhs.uk/Services/opticians/Overview/DefaultView.aspx?id=19232))
- Specsavers, Basingstoke ([www.specsavers.co.uk/stores/basingstoke](http://www.specsavers.co.uk/stores/basingstoke))

- Clapham Optical in Totton ([www.claphamoptical.co.uk](http://www.claphamoptical.co.uk))
- Specsavers in Totton ([www.specsavers.co.uk/stores/totton](http://www.specsavers.co.uk/stores/totton))

### Isle of Wight

- Specsavers in Newport ([www.specsavers.co.uk/stores/iow](http://www.specsavers.co.uk/stores/iow))
- Vision Express at Tesco Extra in Ryde PO33 1QS and in Newport PO30 1TP ([www.visionexpress.com](http://www.visionexpress.com))
- Rutherford (various) ([www.rutherfordeyecare.co.uk](http://www.rutherfordeyecare.co.uk))
- Willets and Doig, Cowes ([www.willettsandoig.com/](http://www.willettsandoig.com/))

**Other:** Moorfields Eye Hospital (various) - [www.moorfields.nhs.uk/content/our-locations-0](http://www.moorfields.nhs.uk/content/our-locations-0)

## Appendix C: SeeAbility Resources

SeeAbility is one of the oldest disability organisations in the United Kingdom and they provide specialist support, accommodation and eye care help for people with learning disabilities, autism and sight loss. They have a range of free, downloadable tools and resources which can support sight tests and good eye care for both adults and children:

- **Finding an optometrist**  
Find your nearest learning disability friendly optometrist by using their search tool: [www.seeability.org/pathways](http://www.seeability.org/pathways)
- **Booking an appointment and attending a sight test**  
There are a variety of Easy Read forms that can be printed and taken to sight tests to help with booking appointments, informing the optometrist about any additional support, and receiving results in clear, easy language: [www.seeability.org/eye-care-factsheets](http://www.seeability.org/eye-care-factsheets)

- **Support for prescribed glasses**

Easy Read information about getting new glasses and using them can be downloaded: [www.seeability.org/eye-care-factsheets](http://www.seeability.org/eye-care-factsheets)

For more information about local schemes for eye care, general eye health, diabetic screening or any other queries, you can visit the SeeAbility website here: [www.seeability.org](http://www.seeability.org).

# Acknowledgements

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## **Dorset, including Bournemouth, Christchurch and Poole**

Bournemouth, Christchurch and Poole Learning Disability Partnership Board; People First Forum & Go Forum; People First Dorset; Healthwatch Dorset; Dorset Clinical Commissioning Group's (CCG) Staying Healthy Action Group; Dorset Advocacy; Dorset Carers Hub; PramaLIFE.

## **Hampshire, including Southampton and Portsmouth**

Hampshire Learning Disability Partnership Board; Hampshire Local Implementation Groups (LIGs); Portsmouth Learning Disability Partnership Board; Healthwatch Southampton; Healthwatch Hampshire; Healthwatch Portsmouth; Strategic Health Facilitators at Southern Health NHS Foundation Trust; Southampton Mencap; Newfields Gardening CIC; Stable Family Home Trust; Autism Hampshire & Serendipity Groups; Minstead Trust; Choices Advocacy; Southampton Special Purpose Service; Way Ahead Day Services Limited.

## **Isle of Wight**

Friends Matter IW and their Carers Support Group located; Isle of Wight Clinical Commissioning Group (CCG) and Healthwatch Isle of Wight.

A big thank you to SeeAbility's Eye Care Champions, who created the Easy Read version of this report.

# Contact Details

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