



LOCSU Learning Disabilities Eye Care Pathway

London pilot

This is the final report on 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 from October 2013 to March 2015.

Executive Summary

Value statements

- People with learning disabilities have the right to access appropriate eye care services.
- People should not be denied access to essential eye care services due to their disability.
- Vision helps people to communicate, understand their world and to keep safe. The value of vision should not be limited to activities such as reading, work and driving.

Key findings

Eye health and general health outcomes

- 30% of all patients were referred on to their GP or Hospital Eye Service for an eye health or other health issue.
- 33% of all patients had a new eye health issue identified.
- Overall, 52% of patients now have an eye health issue identified

This service is essential for identifying and treating serious eye health and general health issues for people with learning disabilities.

Wearing glasses

- Following their sight test, 63% of patients are wearing prescribed glasses.
- 21% of all patients were prescribed glasses for the first time.
- 37% of all patients received replacement glasses.

Refractive error in people with learning disabilities has often not been identified or not acted upon. People with learning disabilities need access to the correct glasses as a basic human right.

Patients who used the service

- For 50% of patients, the date of their previous sight test was more than 2 years ago or unknown.
- 35% of the patients were over 60 years old.
- 70% of patients were from Kensington and Chelsea.

Half of the people with learning disabilities who accessed the service are not known to be having regular eye care. There is a clear demand for eye care for the older learning disabilities population. More patients from Hammersmith and Fulham and Westminster need to access this service.

The Pathway

- From a total of 104 sight tests, 17 were domiciliary.
- 25% of patients asked were referred to the service by their GP.
- 44% of patients asked were referred by someone they know.

To succeed, the service must be well-publicised to GP's, carers, supporters and other organisations and must include domiciliary provision.

The benefits of the LOCSU Pathway in the Tri-Borough area

1. The service has increased access to eye care for a group which has a higher prevalence of sight-related issues than other people.
2. People with learning disabilities have received a quality service which meets their particular needs.
3. Among an ageing population, instances of preventable sight loss have been reduced due to early detection.
4. Increasing access to treatment and surgery has reduced the risk of trips and falls leading to expensive hospital care.
5. More people with learning disabilities have access to spectacles which will enhance their quality of their life and promote independence.
6. Regular eye examinations increase opportunities to detect general health issues such as diabetes.
7. Promotional activities and the accessible report from the optometrist have helped people to be more aware of their eye health, vision and correct use of spectacles.
8. People have gained access to a service they value within their local community and at short notice, potentially avoiding the requirement to access an optometry service at the hospital.
9. Participating optometrists felt that the Pathway gives them more scope to meet patients' needs.
10. Patients and carers commented positively on their experiences of the service.
11. Patients have been directly signposted to the service, avoiding an unnecessary GP referral to the hospital eye service.
12. Patients who subsequently do need to be referred to the hospital eye service are referred to an appropriate clinic relating to the reason for the referral, rather than a general clinic.

Recommendations

1. This report recommends that this eye care pathway should be commissioned within the Tri-Borough. The pilot has demonstrated that the service can be delivered effectively in this area.
2. Establish systems for future data capture and service monitoring and review including monitoring outcomes for patients further along the pathway of care.
3. Assess whether some patients could be successfully seen by this community optometry service, rather than having to travel to access this service at a hospital.
4. On-going promotional work to signpost people to the service is strongly recommended and will need to be addressed. This is particularly true for Hammersmith and Fulham and Westminster. GP's should routinely be asking about eye care in Annual Health Checks for people with learning disabilities.
5. Engage in awareness-raising activities with carers and providers to ensure that good support is provided before, during and after the sight test.
6. Enable non-participating optometry services to inform patients about this service where appropriate in preference to onward referrals to the GP and hospital service.
7. Revisit the distribution of participating practices to ensure there is good geographical coverage in all parts of the Tri-Borough area.
8. Consider expanding the service to include Hounslow CCG and Ealing CCG to match the CWHHE collaborative commissioning partnership.
9. Local Joint Strategic Needs Assessments identify the prevalence of eye health issues for people with learning disabilities to raise awareness of this issue.



How this pathway helps to meet CCG aims and priorities

This pathway will help the Tri-Borough CCG to achieve the following aims –

Full Business Case Tri-Borough CCG Community Ophthalmology Service

Strategic Objectives and Drivers for Change

This project will help to –

- (1) Deliver Shaping a Healthier Future and the Out of Hospital Strategy
- (2) Deliver improved quality of services to patients

NHS Standard Contract 2014/15 for the Community Ophthalmology Service

NHS Outcomes Framework Domains & Indicators

Domain 2 – Enhancing quality of life for people with long-term conditions

Domain 3 – Helping people to recover from episodes of ill-health or following injury

Domain 4 – Ensuring people have a positive experience of care

Domain 5 – Treating and caring for people in safe environment and protecting them from avoidable harm

From the same report –

Scope – Aims of the Service

The primary aims of the service are to:

- Provide care closer to people's homes, in a community environment
- Deliver high quality specialist services that support patients to get the right care first time
- Support the education and up-skilling of referrers, to conduct better ophthalmic diagnosis and condition management in primary care
- Offer a better value service for the NHS through more efficient use of resources

Health and Social Care Act 2012

Duties, under the Health and Social Care Act 2012 to have regard to the need to—

- (a) *reduce inequalities between patients with respect to their ability to access health services; and*
- (b) *reduce inequalities between patients with respect to the outcomes achieved for them by the provision of health services.*

And finally, with partners, to achieve desired improvements in public health that include measuring activity to indicate action towards preventable sight loss as set out in the Public Health Outcomes Framework 2013-2016.

Overview of the pilot

Background information and current eye care provision

Studies have shown that access to eye care is an important issue for people with learning disabilities. In 2011, research published by SeeAbility indicated that:

- Adults with learning disabilities are 10 times more likely to be blind or partially sighted than the general population.
- People with severe or profound learning disabilities are most likely to have sight problems.
- Nearly 1 in 10 adults with learning disabilities are blind or partially sighted.
- 6 in 10 people with learning disabilities need glasses and often need support to get used to them.

Link to research <http://www.seeability.org/>

“A learning disability is reduced intellectual ability and difficulty with everyday activities – for example household tasks, socialising or managing money – which affects someone for their whole life.” (Mencap)

Although they are more likely to experience sight problems, people with learning disabilities actually face additional barriers in accessing the eye care they need. For example –

- The standard 20 – 25 minute GOS sight test is not long enough for every person with learning disabilities. In some instances, additional time is required in a sight test to ensure effective communication and a pace of testing and explanation that is comfortable for the patient.

- Optometrists may also require additional time to gather information about the particular needs of a new patient with learning disabilities and to share final outcomes from the sight test.
- Some optometrists may feel that they lack the confidence, skills or experience to carry out an eye examination for a patient with learning disabilities.

As a result of the prevalence and access issues described above, people with learning disabilities do not currently have equitable access to the eye care they require. The following situations exist –

- Some people **are not having sight tests at all**. This may be because of a poor previous experience, because it is assumed that the person's disability precludes them from having a sight test or because the importance of regular sight tests is not fully understood.
- Some people will be having **occasional sight tests**. One of the factors here will be that the person has not found an optometrist who they feel is able to meet their needs.
- Some people will be **accessing hospital optometry services** even though these may be further away than their local community optometry services. The number of patients this covers is not known for the purposes of this report.
- Some people with learning disabilities will be **accessing appropriate regular eye care** with an optometrist who knows them well and is able to meet their eye care needs

Tackling eye care inequalities

Since 2005, SeeAbility has been working to increase access to eye care and vision services for people with learning disabilities. Through our work, we understand the importance of regular sight tests and we recognise that without this:

- People with learning disabilities are at risk of avoidable sight loss due to the effect of undiagnosed eye conditions.
- People with learning disabilities are struggling with poor vision because they do not have the spectacles they require to correct a refractive error.
- Carers and support staff do not know how well someone can see, making it impossible for them to provide the right care for that person.

In recognition of the eye care needs of adults with learning disabilities, in April 2012, the Local Optical Committee Support Unit (LOCSU) launched its Community Eye Care Pathway for Adults and Young People with Learning Disabilities.

<http://www.locsu.co.uk/community-services-pathways/community-eye-care-pathway-for-adults-and-young-pe>

The Pathway provides:

- An enhanced sight test in a community setting – this gives optometrists more time to familiarise patients and their carer with the procedures and equipment at the time of the sight test and also gives time for repeat visits to complete procedures where needed
- Better preparation for patients and greater information sharing with the optometrist before the sight test via SeeAbility's 'Telling the optometrist about me' form, which helps make the experience a positive one
- Better feedback from optometrists to patients, regarding sight test results, using SeeAbility's 'Feedback from the Optometrist about my eye test' form.

SeeAbility supports the LOCSU Pathway and is keen to see it adopted around the country. Consequently, SeeAbility secured funding from the LOC Central Fund to trial the Pathway within a commissioning area. SeeAbility initially elected to work with Kensington and Chelsea because of existing links between SeeAbility, the Optometry Advisor and the Health Facilitator for People with Learning Disabilities from the borough. It was then agreed that it would be beneficial to widen the pilot out to the Tri-Borough area to include Hammersmith and Fulham and Westminster which would tie in with local commissioning practices.

Setting up the pathway in the Tri-Borough area

First of all, a project group was formed consisting of SeeAbility, the Optometry Advisor and a lead person from each borough's Community Team for People with Learning Disabilities. Where possible, this was the borough's Health Facilitation lead for people with learning disabilities. As per the LOCSU Pathway, it was agreed that optometrists would receive an additional fee of £60 per sight test (practice-based or domiciliary) which would be paid by SeeAbility.

This group agreed the data that would be collected from the sight tests. This data was returned to SeeAbility on a Word document which could be scanned if necessary. This method was satisfactory for the purposes of the pilot but consideration should be given to using an optometry software programme to capture data, process payments and provide ease of data analysis.

The Optometry Advisor sent a communication to all local contractors and performers inviting Expressions of Interest in the pilot. Interested optometrists attended an accreditation event on 26th September 2013. The event included:

- A CET (Continuing Education and Training) lecture on sight tests for people with learning disabilities provided by Louise Stalker, Optometrist - Action for Blind People
- A talk on prescribing spectacles for people with learning disabilities by Jayshree Vasani - Dispensing Optician
- Guidance on working effectively with people with learning disabilities by Sheila Rodgers - Team Manager, Kensington and Chelsea Community Learning Disabilities Team
- Description of the mechanics of the Pathway by Stephen Kill - SeeAbility

Support for the planning of the pilot was also received from Kensington and Chelsea and Westminster LOC and Ealing, Hammersmith and Hounslow LOC.

Once the list of participating optometry services was finalised, a promotional flyer was created for each borough <http://kcwloc.com/eyetest/>. The flyers included a list of optometry services and explained how they could be accessed. In addition, participating practices were given a sticker to place in their window advertising the service (Appendix 1).

The project group liaised with Peter Beard, Senior Commissioning Officer Learning Disabilities and Carers, Inner North West London Primary Care Trusts and Ben Farrelly, Senior Commissioning and Procurement Manager Dental, Pharmacy and Ophthalmic & GP Services NHS North West London.

Applying the pathway in the Tri-Borough area

1. Patient chooses optometrist from promotional flyer
2. Patient or carer arranges sight test
3. Patient and carer complete SeeAbility's "Telling the optometrist about me" form to give to the optometrist
4. Sight test carried out using Reasonable Adjustments as required over 1 or more appointments totalling 45 – 60 minutes
5. Optometrist gives patient completed "Feedback from my optometrist" form
6. Arrangements for glasses or onward referral made as usual

Promoting the pathway

The numbers of people with learning disabilities identified in the 3 boroughs are:

Borough	Numbers of people with learning disabilities
Westminster	551
Hammersmith and Fulham	373
Kensington and Chelsea	210
Total	1134

It was acknowledged that it would be crucial to promote the Pathway effectively to give people the opportunity to use it. Many people with learning disabilities are reliant on carers and supporters to facilitate their access to eye care services.

The following promotional work was undertaken throughout the duration of the pilot:

- 2 events for people with learning disabilities, carers and professionals to promote the Pathway
- Attendance at a variety of local events, groups and meetings to discuss the Pathway
- Details of Pathway circulated to GP surgeries, Learning Disability Teams and Care Managers, local support providers and a variety of groups for people with learning disabilities and carers
- Window stickers were devised and placed in participating optometrist's windows to promote the pilot. (Appendix 1)

Based on the data below, and given the degree of promotional work undertaken, the project group was a little surprised that it took nearly 18 months to reach our target of 100 sight tests. This may indicate the challenge that people with learning disabilities can have in accessing services in the community. This will be an area for further discussion and activity.

Examples of further awareness-raising activity to promote this service include –

- Working with local providers of support to people with learning disabilities to achieve SeeAbility's Eye Care and Vision Charter. The Charter demonstrates good support around eye care and vision.
- Local learning disability organisations offering training in looking after your eyes to other people with learning disabilities. This is available through SeeAbility's Peer Educator Network.

Data from the pilot

Age of patients

Between October 2013 and March 2015, SeeAbility was informed of 104 sight tests completed under the pilot. 52% of sight tests were with females and 44% with males (4% not recorded). The oldest patient was 87 years old, the youngest was 18.

Age of patient	Percentage
0 - 30	16%
31 - 60	49%
61 plus	35%

This age distribution demonstrates a clear demand for eye care for the older learning disabilities population.

Patients were from the following boroughs:

- Kensington and Chelsea 70%
- Hammersmith and Fulham 14.5%
- Westminster 13.5%
- Ealing 2%

This shows that additional promotional activity is required to increase the proportion of patients from Hammersmith and Chelsea, and Westminster.

Details of which optometry services were used:

Not all of the participating optometry services saw patients in this pilot. 6 out of 11 practices did see patients but none of the Westminster practices did. It is possible that some Westminster patients are accessing the local hospital for their eye care although a more detailed analysis would be required here.

- Kensington and Chelsea 2 out of 3 practices used
- Hammersmith and Fulham 4 out of 5 practices used
- Westminster 0 out of 3 practices used
- Domiciliary 3 out of 4 companies used

From a total of 104 sight tests, 87 took places in practices and 17 were domiciliary, demonstrating that some patients will require a domiciliary service.

Date of most recent sight test:

- In the last 2 years 50%
- Over 2 years ago 19%
- Unknown 31%

This indicates that half of the people with learning disabilities who accessed the service are not known to be having regular eye care.

How patients heard about the service:

This question was asked for 31% of all patients.

- Told by family, friend, carer 44%
- Existing patient 28%
- GP referral 25%
- Hospital eye service 3%

This suggests that effective promotion of this pathway to a range of different groups is not only worthwhile, but actually essential to ensure there is sufficient activity.

Spectacles prescribed:

Following their sight test, 63% of patients wear glasses.

- 21% of all patients received their first ever pair of glasses.
- 37% of all patients were issued with replacement glasses.
- 5% of all patients have kept their existing glasses

Of the 58% of patients who were prescribed with new glasses.

- 1 pair glasses prescribed 42%
- 2 pair glasses prescribed 16%

Eye health and general health issues

- 32% had an existing eye health condition.
- 33% had a new eye health issue identified
- Overall, 52% of patients now have an eye health issue identified

Here is a list of existing and newly-identified eye health issues:

Eye health issue	Existing (%)	Newly-identified (%)
Lens opacities	7	16
Hemianopia	1	0
Myopia	1	0
Diabetic retinopathy	4	1
Keratoconus	3	3
Photophobic	1	0
Itchy eyes or related	3	3
Squint / strabismus	2	0
Amblyopia	1	0
Alternating exotropia	1	0
Watery tired eyes	1	0
Strabismus, corneal scars & cataract	2	0
Not stated	5	0
Uveitis	0	1
High intra-ocular pressures	0	6
Arcus	0	1
Diplopia	0	1
Highly astigmatic	0	1
Total	32	33

Onward referrals:

- 30% of all patients were referred on to their GP or Hospital Eye Service for an eye health or other health issue.

Significantly, 2 of these patients are scheduled to undergo cataract surgery in May 2015. One of these was a new patient to a participating practice.

Here is the breakdown of reasons for onwards referral:

Reason for referral	Number (%)
Cataract surgery	10
Keratoconus	4
Uveitis	1
Glaucoma / high intra-ocular eye pressures	5
Diabetes-related	6
Diplopia	1
Blepharitis	1
Dermatitis	1
Not stated	1
Total	30

Stakeholder feedback

Some of the patients and carers agreed to give their feedback on the service by questionnaire, as follows.

Responses from people with learning disabilities

- 80% were happy with their sight test.
- 92% said the optometrist and their staff were friendly
- 92% felt they had enough time in their sight test
- 93% would be happy to see the same optometrist again
- 87.5% said their new glasses helped them

Further comments -

- I was happy because the optician took his time and explained all the procedure to me
- This is very different from the first eye check I had in a different opticians.
- They were talking to me. They explained things and smiled.
- They were nice. They talked slowly so I could understand.
- They didn't speak to me that much.
- The staff in the opticians are very friendly. They help me to understand my health.
- I can understand the information I read better than before as I never had an eye test before.
- My glasses help me all the time when I am watching TV because I cannot see small print. On the computer it has to be large letters with easy read and pictures.
- Not sure if my glasses help me to see things or not.

Responses from carers and supporters

- 100% thought that regular eye examinations are important for people with learning disabilities
- 100% felt that the sight test went very well
- 100% felt there was enough time in the sight test
- 100% said the optometrist and their staff were friendly
- 86% said the optometrist did very well at communicating and explaining what was happening
- 100% thought that the optometrist used testing methods suitable for the person
- 67% said that the person was subsequently wearing their spectacles as advised

Further comments –

- A little unsure but being in a familiar environment helped him relax. He could leave the room and then come back when he was ready to continue (domiciliary examination).
- (The optometrist) followed instructions from facilitator and support worker on how to communicate and applied appropriate communication tools.
- Patient and friendly – listened to staff on how best to support / communicate.
- I was very impressed, very pleasant staff, not rushed.
- The optician was friendly and spoke clearly to the service user in a way that she will understand. During the test he used pictures of objects and animals that the service user was able to identify. As a result, the optician was able to make a good judgement.
- Late – not good for people with LD and autism.
- Was unable to have eye test previously as he refused.
- Prescribed glasses for the first time. Previous optician did not, as assumption was they would not be tolerated.

Additional feedback from Westminster identified two particular groups that can have particular difficulty in accessing eye care –

- People with profound and multiple learning disabilities - some wheelchair users had difficulty accessing the entrance and examination room of a participating practice.
- People with minimal support – some people may miss out on eye care due to lack of awareness, lack of formal support at necessary times or conflicting support needs within limited hours.

Feedback from participating optometrists:

“Regular sight tests are important for everyone. I think this pilot reminds carers that there is real value in having an eye examination for their clients to achieve optimum vision and have a regular eye health check. A carer may not always realise that a sight test can be tailored to suit the individual needs of a patient taking into account communication or other difficulties.”

“The status quo is of patients with LD being examined in secondary care due to the lack of such a service in the community. If patients with LD are seen in the community, more LD patients are likely to attend for an eye examination due to the ease of proximity of the service.”

“Communication and cooperation were a little challenging. Kay Pictures were very useful with the patients I saw, particularly with a non English speaker.”

“The main difficulty is the time factor but when I did not manage to get a prescription in the allocated appointment time, I rebooked the patient.”

“Patients that did little before the sight test received glasses which have changed their life in the way they become more interactive and showed more interest in watching TV rather than just sit with their head down.”

“Some carers have been very good in warning me that the patient does not like contact or to be left in the dark but a couple of them left the practice as soon as the patient was in the consulting room to do their shopping or go to the bank.”

“A carer may not always realise that a sight test can be tailored to suit the individual needs of a patient taking into account communication or other difficulties.”

“The pilot has also demonstrated the need for ophthalmic performers to be given more support to enable them to carry out eye examinations on patients with LD.”

“CCGs should seriously consider the implementation of a primary eye care pathway for patients with LD in their catchment area. Such a service will provide easier access to eye exams to patients with LD which would ultimately result in savings being made by seeing patients with LD outside secondary care.”

Conclusion

This pilot of LOCSU’s eye care pathway for adults with learning disabilities recorded a total of 104 sight tests.

This report has identified how the pilot enabled people with learning disabilities to access effective eye care services with significant outcomes in terms of glasses prescribed and eye health and general health issues identified.

This service provides reasonable adjustments which have increased access to eye care for a group which has a higher prevalence of sight-related issues than other people.

SeeAbility believes that the pilot has shown the need for this service to be commissioned in the Tri-Borough area and the pilot has successfully brought together local eye care and learning disability professionals for the benefit of patients with learning disabilities. The pilot has increased access to quality eye care, spectacles and treatment for this “hard-to-reach” group of people.

SeeAbility will circulate this report throughout Tri-Borough and nationally and will be willing to discuss its content with local commissioners and interested parties.

Recommendations

1. This report recommends that this eye care pathway should be commissioned within the Tri-Borough. The pilot has demonstrated that the service can be delivered effectively in this area.
2. Establish systems for future data capture and service monitoring and review including monitoring outcomes for patients further along the pathway of care.
3. Assess whether some patients could be successfully seen by this community optometry service, rather than having to travel to access this service at a hospital.
4. On-going promotional work to signpost people to the service is strongly recommended and will need to be addressed. This is particularly true for Hammersmith and Fulham and Westminster. GP's should routinely be asking about eye care in Annual Health Checks for people with learning disabilities.
5. Engage in awareness-raising activities with carers and providers to ensure that good support is provided before, during and after the sight test.
6. Enable non-participating optometry services to inform patients about this service where appropriate in preference to onward referrals to the GP and hospital service.
7. Revisit the distribution of participating practices to ensure there is good geographical coverage in all parts of the Tri-Borough area.
8. Consider expanding the service to include Hounslow CCG and Ealing CCG to match the CWHHE collaborative commissioning partnership.
9. Local Joint Strategic Needs Assessments identify the prevalence of eye health issues for people with learning disabilities to raise awareness of this issue.

APPENDIX 1 – promotional sticker for optometrists’ practice windows



SeeAbility would like to acknowledge the Central LOC Fund for their support of this pilot.



Central (Local Optical Committee) Fund

Links to further information -

Telling the optometrist about me -

https://www.seeability.org/uploads/files/PDFs_Books_Easy_Read_/Telling_optometrist.pdf

Feedback from the optometrist -

https://www.seeability.org/uploads/files/PDFs_Books_Easy_Read_/Feedback_from_the_optometrist.pdf

SeeAbility's Eye Care and Vision Charter and Peer Educator Network

<https://www.seeability.org/our-services/advisory-services/>

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