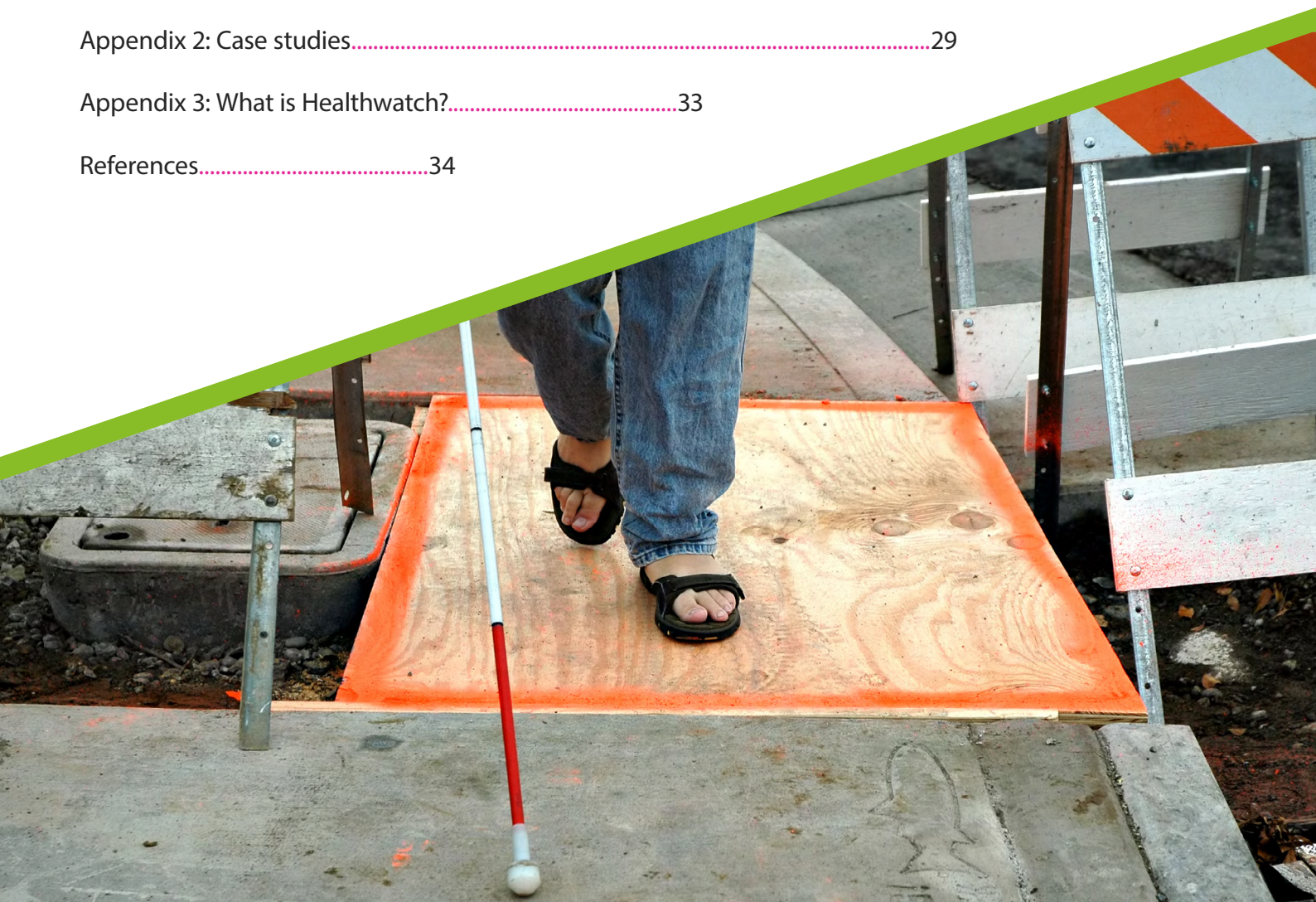


What challenges do people with sight loss face accessing vision rehabilitation services in Birmingham?



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What challenges do people with sight loss face accessing vision rehabilitation services in Birmingham?

Executive Summary

What we heard:

Healthwatch Birmingham investigated the challenges people with sight loss face when they access Birmingham City Council's vision rehabilitation services. We spoke to 33 individuals who were either registered sight impaired or severely sight impaired and a small number who were not yet registered.

Overall, the people we spoke to agreed on the importance of vision rehabilitation services. Vision rehabilitation support was seen as important to people's independence, confidence and security as well as having an economic benefit. Those that received rehabilitation indicated that this helped them be an active member of their community. However, people with a visual impairment face challenges when they access Birmingham City Council's vision rehabilitation service.

These challenges occur at four different points in their engagement:

Initial contact with the vision rehabilitation team following diagnosis - referral

- The length of time for the vision rehabilitation team to contact people when they receive a Certificate of Visual Impairment (CVI).
- Variability in the time taken to contact people who have different registrations and individuals at different stages of their journey. For instance, some individuals have little or no contact with the vision rehabilitation team when they are registered sight impaired and only tend to have contact when their registration changes to severely sight impaired/blind.
- No systematic process for contacting individuals who have not reached the threshold for registration but have sight difficulties that impede their independence.
- Lack of information about what registration means and what individuals can expect following registration.

Vision rehabilitation assessment - assessment of needs and specialist assessments

- Assessments are directed by the assessor and do not seem comprehensive or focused on the individual and their needs. Some felt that assessments were not performed by a vision rehabilitation specialist.
- Assessments are not holistic and therefore fail to take into account other conditions and issues such as mental health or financial and social welfare concerns.
- Lack of an assessment report and plan that outlines the support being offered.

- Lack of referral to other services, information or organisations based on assessment of needs.
- Assessments (including the support offered) is geared towards people who are less capable and independent. As a result, some said they found themselves having to overstate or exaggerate their difficulties to ensure that they receive support.
- Poorly resourced service.

Receiving vision rehabilitation support – in-depth rehabilitation

- Support is hurried and not enough time is given to learn the skills necessary to be independent. Some found the support inflexible and some felt that they did not receive the support for as long as they needed it.
- Support does not meet their needs. This relates to the assessment, with some people indicating they received items that they actually do not need or couldn't use.
- No plan or communication about the assessment outcome, meaning service users are unsure of what support to expect.
- Lack of clarity about who is responsible or who to contact about different aspects of rehabilitation.
- Not everyone we spoke to felt that they had the opportunity to return or re-refer into the vision rehabilitation service when they could not complete their skills training.
- Lack of signposting to information, advice and complementary support when receiving rehabilitation support.

Post vision rehabilitation support – follow-up and reviews

- People did not have follow-up assessments or review dates built into their support plan nor were any reviews carried out. For those that received further support, such as mobility training, an assessment was only carried out when the individual had difficulties such as a fall.
- A majority were unaware they could re-refer themselves to the vision rehabilitation service, with only one person telling us they had been left an open channel to access support when they were ready.
- There is no single point of contact, therefore people don't know who to call for different concerns when they arise.

What would improve people's experience of accessing vision rehabilitation services?

We asked people what worked well and what could improve their experience. People told us the following steps would improve their experience of accessing vision rehabilitation services provided by Birmingham City Council:

- Clarity about how and who to contact for support.
- Clarity about the registration process and referral routes.
- Support that helps individuals to live as independently as possible.
- Better and more accessible information and advice.
- Comprehensive assessment and support that addresses various aspects from an individual's eye health to emotional, physical, financial and social needs.
- More follow-up calls and reviews.
- Better co-ordination of services.
- Flexible rehabilitation support that meets people's needs and preferences.
- Clarity about how to access vision rehabilitation in the future if required. In addition, the process including further assessments, should be simplified and less rigid.
- Signposting to other relevant organisations and services.
- A standalone vision rehabilitation service providing direct access to vision rehabilitation officers.
- Assessment and support from a specialist with appropriate skills, knowledge, training and qualifications.
- A better resourced service.
- More awareness of the support on offer.
- Access to technology to aid independence.

Next steps

We sent the draft report to Birmingham City Council's vision rehabilitation service and asked them how they plan to address the issues we identified. Their action plan is below and the full response can be found in Appendix 1.

We will publish a follow-up report in six months. This will include evidence of actions and improvements undertaken by Birmingham City Council's vision rehabilitation teams.

Case studies of interviewees can be found in Appendix 2.

Healthwatch Birmingham will aim to hear more experiences about accessing vision rehabilitation support in Birmingham. If you are accessing Birmingham City Council's rehabilitation service, please share your experiences with us through our online feedback centre, our information and signposting line and our community engagement work (see Appendix 3 for further details).

Birmingham City Council action plan

Birmingham City Council's response clarifies the set-up of the vision rehabilitation service in Birmingham. The response also highlights the changes that have taken place following a review of the vision rehabilitation service in 2018. Improvements include a single point of access to vision impairment rehabilitation, joint working with charity organisations and improved engagement with service users.

The response takes on board the experiences shared by citizens and commits to using these to making improvements to service delivery. The actions Birmingham City Council has outlined in response are below, and the full response can be found in Appendix 3.

- Visual Impairment Rehabilitation officers will be adopting the 3 Conversation model to ensure our interventions remain person centred and strength based, exploring the needs of our citizens holistically with a focus on how their sight loss and possible dual sensory loss impacts upon their daily living. We are already in the process of adapting our paperwork. <http://partners4change.co.uk/the-three-conversations/>
- As part of the 3 Conversation model we will be reviewing the sight loss journey for our citizens to include a review of interventions provided to them as well as provision of conversation assessment documents in accessible and preferred formats.
- We have commenced recruitment process for an additional Visual Impairment Rehabilitation Officer.
- We will deliver sight loss awareness training to contact centre staff who will be the first responders to citizens and professionals contacting Birmingham City Council (BCC) for referrals and queries.
- Following certification citizens are contacted within two weeks. However, we acknowledge that this is currently via correspondence and so we will explore possibilities of developing this into a more personal and direct form of contact.
- We will work with the appropriate colleagues to improve information available on our BCC website, accessibility and ease of use and navigation.
- We are already working closely in partnership with Focus and RNIB and will continue to develop referral pathways and the provision of the Information, Advice and Guidance (IAG) Service and Living with Sight Loss Courses to maximise a fluid and positive journey for our citizens.
- We are currently revising and updating all our factsheets which are sent out to all citizens registered and will make them accessible for relevant professionals including Eye Clinic Liaison Officers (ECLOs), Low Vision Clinics and sight loss organisations. We will also utilise these in the promotion of our services to GPs, specialists and generic agencies and networks.
- We will develop an additional information leaflet which sets out local and national Sensory Impairment services and organisations with contact details in accessible format of large print.
- We will explore possibilities to have physical presence in attendance in appropriate hubs and venues starting alongside ECLOs in hospitals including Low Vision clinics.

The following actions will commence with immediate effect. However, we recognise that a more realistic timescale for achieving these will be 12 months.

- The Visual Impairment IAG Service contract includes sight loss awareness training for professionals which we will continue to participate in.
- We will explore systems and processes of how the most beneficial way is to maintain contact with citizens on the register.

- We have commenced an overall review of the service and the future structure of the Visual Impairment Rehabilitation and Sensory Impairment teams.
- We would be hopeful to explore with third sector sight loss organisations attendance at their hubs as well as resource centre based at a BCC accessible building.



Introduction

What did we investigate?

In 2019, NHS England asked Healthwatch England (via local Healthwatch) to engage with the public on the content of the NHS Long Term Plan (LTP). During the engagement we heard from targeted groups about what is important to them to live a healthy life and the support needed to be independent. A focus group, held with people with sight loss, told us the importance of:

- Support that also focuses on the health and wellbeing impact of sight loss such as depression, social isolation and loneliness.
- Good support from officers such as Eye Clinic Liaison Officers (ECLOs), and vision rehabilitation officers.
- Developing the necessary skills to live with sight loss and maintain independence.
- Access to comprehensive assessments that balance different aspects of a person's life.
- Health and social care professionals who are compassionate, understand the challenges of sight loss, and have knowledge of visual rehabilitation services and support.
- Accessible information and advice.

Based on the feedback Healthwatch Birmingham heard, it was our impression that ***some people with sight loss in Birmingham experience unequitable barriers to accessing vision rehabilitation services.*** We were therefore keen to hear from more people. The key question this project aimed to address was ***What challenges do people with sight loss in Birmingham experience when accessing vision rehabilitation services as outlined in the Care Act 2014?***



Background

Sight loss and the Care Act 2014

Sight loss is a term used to refer to someone who has no sight or whose sight is impaired beyond the use of correctional glasses or lenses. Sight loss has a considerable impact on different aspects of a person's life. It is forecasted that the number of people living with sight loss in England will double by 2050 to four million, placing considerable demand on health and social care services¹. Consequently, vision rehabilitation services are considered key to prevention, supporting independence and reducing demand on health and social care services. The Care Act 2014 further entrenched the importance of vision rehabilitation, by requiring all councils in England to provide this service.

The Department of Health's (2014) Care and Support Statutory Guidance states that:

Local authorities should consider securing specialist qualified rehabilitation and assessment provision (whether in-house, or contracted through a third party), to ensure that the needs of people with sight impairment are correctly identified and their independence maximised. Certain aspects of independence training with severely sight impaired and sight impaired people requires careful risk management and should only be undertaken by professionals with relevant experience and training. This type of rehabilitation should be provided to the person for a period appropriate to meet their needs. This will help the person to gain new skills, for example, when training to use a white cane. As aspects of rehabilitation for people with sight impairment are distinct from other forms of reablement, it should not be time prescribed. Local authorities should also refer to the Association of Directors of Adult Social Services' (ADASS) position statement of December 2013. This makes it clear that rehabilitation for sight impaired people is a specific form of reablement. However, there are some intrinsic characteristics which define rehabilitation as being distinct from other forms of reablement. It is therefore not appropriate to take a one-size-fits-all approach, and local authorities need to ensure that individual needs are met appropriately.

ADASS² highlights key requirements in the Care Act for local authorities that directly affect people with vision impairment:

- Contact with a visually impaired person should be made within two weeks of a Certificate of Visual Impairment (CVI) being issued and assessments must be carried out by a person with the "necessary skill, knowledge and competency."
- Rehabilitation must be provided based on people's needs and should not be limited to six weeks.
- Minor aids and adaptations up to the value of £1,000 must be provided free of charge.
- The wellbeing of service users and their carers must be promoted. Wellbeing is defined as: personal dignity and control over daily life, physical/mental health, social/emotional wellbeing, protection from abuse/neglect, participation in work/education/training/recreation, economic wellbeing, and suitable living accommodation.
- "Preventative" services should be prioritised to prevent, delay or reduce the care needs of both adults and their carers.

¹ Thomas Pocklington (2015) Rehabilitation Services: What is the evidence, <https://www.pocklington-trust.org.uk/project/limited-evidence-hinders-potential-for-improving-sight-loss-rehabilitation-research-finds/>

² <https://www.adass.org.uk/blog-2015-care-act-and-visual-impairment-barry-porter/>

- Local authorities must provide information about available care and support and ensure their information is accessible to people with vision impairment.

Vision rehabilitation support is aimed at helping individuals to adapt to sight loss by providing training in daily living skills, mobility and communication (e.g. hearing aids, adaptations and equipment). Evidence³ shows that vision rehabilitation services have a positive impact on individuals' daily lives and emotional wellbeing, as well as an economic value by reducing or delaying the need for health and care needs. The Royal National Institute of Blind People (RNIB) identifies four key areas of vision rehabilitation that benefit people with sight loss, namely functional independence, personal safety, emotional wellbeing and social participation.

Key stages of a vision rehabilitation service are referral, initial assessment of client needs, specialist assessment, in-depth rehabilitation and follow-up. RNIB has produced three easy steps that councils need to take to ensure that they are meeting the needs of individuals:

- See: everyone with a visual impairment must receive a specialist face-to-face assessment.
- Plan: everyone must have a plan in place, identifying the outcome of the assessment. The first two steps must take place within 28 days of first contact with the local authority.
- Provide: any agreed vision rehabilitation support must start within 12 weeks of the person's initial contact with the local authority.

Sight loss and vision rehabilitation services in Birmingham

In Birmingham, services for adults with a visual impairment are provided by the Birmingham City Council Visual Impairment Service, which has a social work team and a rehabilitation team. Potential service users do not have to be registered as blind or partially sighted to apply for these services. According to a 2018 review of sight loss services in Birmingham, 8,620 people are registered as living with sight loss, 4,035 (47%) are registered as blind (or Severely Sight Impaired) and 4,585 (53%) as partially sighted (or Sight Impaired).

However, RNIB estimates that 27,570 is a truer reflection of sight loss in Birmingham.⁴ This is because some people choose not to register, whilst others are waiting for treatment and not given a certificate that precedes registration with the council, whilst for others their ophthalmologist may not understand the benefits of registration.

CASE STUDY

*Mrs G indicates she never had any direct contact with Birmingham City Council after registering as sight impaired. She says that through the instigation of a charity organisation, someone from the council rehabilitation team visited her and put grab rails outside her house, widened her steps and put rails up the stairs. No-one from the council came to see what she needed after this. Mrs G has noticed that her eye sight has deteriorated over the past three years. Although she goes for frequent hospital checks at hospital, she still has not had any contact from Birmingham City Council or any reviews of her condition.**

*additional case studies can be found in Appendix 2

³ RNIB (2017) Demonstrating the impact and value of vision rehabilitation, <https://www.rnib.org.uk/sites/default/files/Demonstrating%20the%20impact%20and%20value%20of%20vision%20rehabilitation%202017.pdf>

⁴ West Midlands Local Eye Health Network (LEHN) and England Vision Strategy (2018) Birmingham and Solihull Eye Health and Sight Loss Evidence Base, <https://www.birminghamandsolihullccg.nhs.uk/about-us/publications/strategic/2308-birmingham-and-solihull-eye-health-sight-loss-evidence-base/file>

Methods

What did we do?

The first stage of research involved speaking to third sector organisations that work with people with vision impairment in Birmingham. We spoke to the Macular Society, Thomas Pocklington Trust, Focus Birmingham and RNIB to understand the pathway for people with sight loss in Birmingham, what services they access for support and the main challenges.

The second stage involved contacting the vision rehabilitation team at Birmingham City Council, to outline the focus of our research and their responsibility for actions to be taken.

We accessed participants through third sector organisations, advertisements on the Healthwatch Birmingham website and social media.

Semi-structured interviews were carried out face-to-face and via telephone to understand the lived experience of those that accessed or attempted to access vision rehabilitation services.



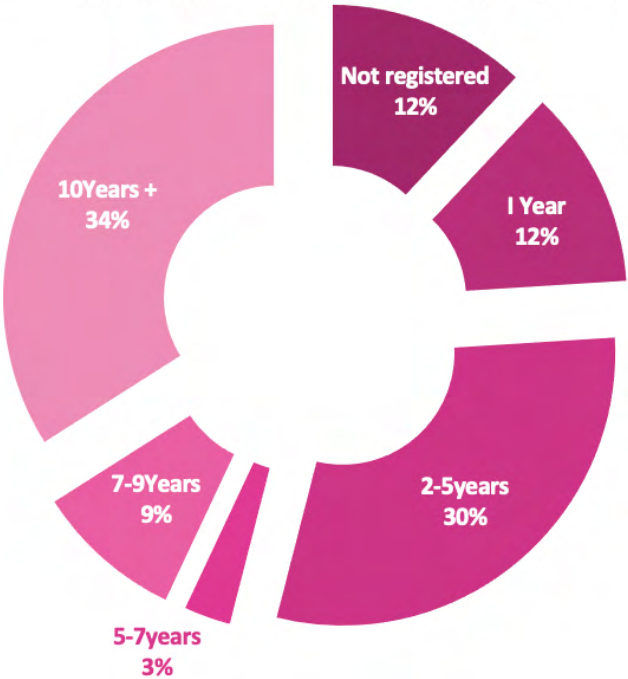
We are grateful to third sector organisations in Birmingham that supported us in defining the focus of this study and helped us to gather feedback from the people they support. Key to our study were Focus Birmingham, RNIB, Thomas Pocklington Trust Birmingham, and the Macular Society. We also received support from New Outlook, Birmingham Guide Dogs, Queen Alexandra College and Sense. We would also like to thank Birmingham City Council's vision rehabilitation team for their support.

Who did we speak to?

33 individuals who have sight loss and have attempted to or have accessed vision rehabilitation services in Birmingham were interviewed by Healthwatch Birmingham staff.

Demographics of Participants

Number of years registered with Birmingham as blind/partially sighted



Gender

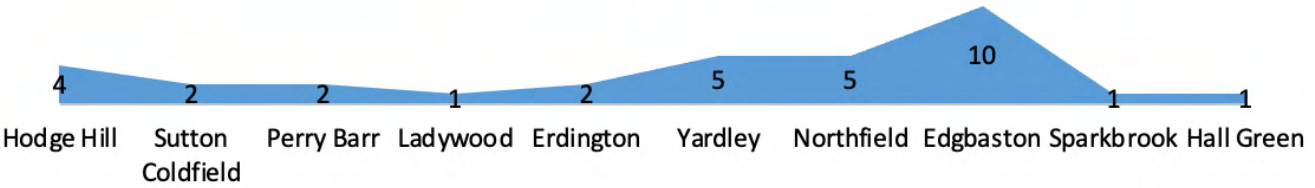
61%



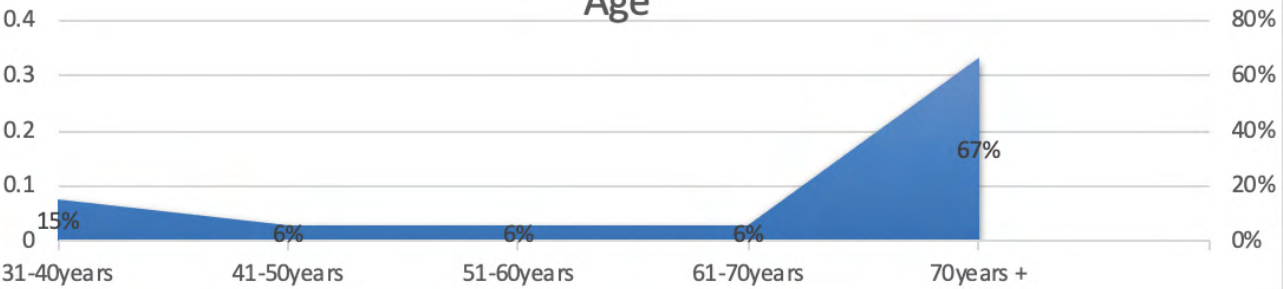
39%



Participants by district



Age



Findings

Our research indicates that people with sight loss have variable experiences at the following stages in their engagement with Birmingham City Council's vision rehabilitation service:

- Initial contact with the vision rehabilitation team following diagnosis – referral
- Vision rehabilitation assessment – assessment of needs and specialist assessments
- Experiences of receiving vision rehabilitation support – in-depth rehabilitation
- Post vision rehabilitation support – follow-up and reviews

Initial contact with the vision rehabilitation team following diagnosis – referral

CASE STUDY

Mrs B was registered as blind after 10 years registered as partially sight impaired. She says that it was only after her registration changed that the council offered sufficient support. She was asked if she wanted help and she agreed because she could no longer drive, cook or safely move around. She was sent an assessment form and independence allowance form which her eyesight meant she could not complete. The council sent someone to complete the form with her and Mrs B told them about her problems with cooking and other activities. Following the assessment, she received a long letter identifying how difficult it was for her to complete various household tasks. Soon after, she received support that enabled her to get a carer to help her with daily living activities such as cleaning and cooking.

There are three main routes to contacting vision rehabilitation services, at which point the council offers the opportunity to register as blind or partially sighted. First, the Care Act 2014 requires local authorities to make contact with the individual two weeks after the individual is issued with a certificate of visual impairment (CVI). Second, individuals can refer themselves into the service regardless of whether they have a CVI and request rehabilitation support. Third, referrals can be made by other organisations that support people with a visual impairment.

The main concerns were:

The length of time it takes to contact people when they receive a CVI

Some people we spoke to were contacted within two weeks of being registered as mandated by the Care Act, as this participant indicates "***following my diagnosis, the council contacted me after a couple of weeks and sent me a registration card. The council sent me something to fill in which one of my daughters filled and then the card came after. There was no explanation of what registration meant.***" However, we found that for most people we spoke to, a month was the minimum length of time taken to be contacted by the council, with others having to wait for over a year.

I was registered last year as blind and I have the council's yellow card. I was supported by the Eye Clinic Liaison Officer to get in touch with the council. After I received a CVI the council got in touch fairly quickly, about six weeks. They made contact through a letter. After that, nothing. No-one visited me or spoke to me about my needs. I have been registered for a year and have had no contact. The impact on my life of sight loss has been tremendous. I can't see to write or read, my husband does it all for me. I can move about in the house but not outside, unless I am familiar with the route. I don't go out a great deal by myself. If I know there is a crossing then I can cross the road. Obviously, shopping is difficult.

After I was diagnosed as severely sight impaired at the hospital they came out after about three months. The reason the social worker came is because I had had a bad fall in the bathroom and broke the toilet cistern. After that we were advised to speak to adult social services about safety by the man who came to fix the toilet.

In addition, it can take a long time for individuals to receive their registration cards, resulting in a long wait to start a rehabilitation assessment and receive appropriate support.

I got registered as severely sight impaired/blind at the hospital in September 2019. It was 10 weeks before I actually had the certificate from the council and the whole process seemed very odd. I felt like there was one person in an office doing everything at the council. The first time she said, 'I don't understand this paperwork, I will call you back' and she never called again. After three weeks, I got in touch and she said, 'Oh, I have your paperwork here and I will get in touch.' That took another four weeks. I think that she was just over stressed, just imagine this one girl in the office on her own surrounded by all these things, that's how I felt. The rehab officer came out not very long - about two or three weeks - after I received the registration card and had a look around.

Variability in the time taken to contact people who have different registrations and at different stages

The Care Act 2014 requires local authorities to maintain registers for blind and partially sighted people. It also specifies that service planning should include people who have reduced or low vision but have not yet met the threshold for registration. Ideally, it should not matter whether you have a CVI or not, or whether you are registered as partially sighted or blind, in order to receive support from the vision rehabilitation service. Indeed, the visual impairment team at Birmingham City Council told Healthwatch Birmingham that they offer support, if needed, to those with a visual impairment regardless of the type of registration, as well as those not registered. However, the experiences of contact with the vision rehabilitation team for the people we spoke to demonstrate variability between those who are sight impaired and those registered as blind, and for individuals at different stages of their journey. One individual told us that, although she received the registration card from the vision rehabilitation service, no-one contacted her to carry out an assessment and provide support. It was only once she started attending coffee morning sessions for people with sight loss, and the organisation identified she was having difficulties, that they called the vision impairment team and she received an assessment and support.

Some people also felt that they received more support from the vision rehabilitation service once their registration changed from sight impaired to severely sight impaired/blind.

It is important to note that there are those that chose not to receive any support after contact with the vision rehabilitation service. Three people told us that they chose not to receive support either because they had a family member who could support them, or preferred to have a support worker, or felt that the support from charity organisations was sufficient at the time. However, most people that had had a change in their registration felt that there was a difference in support.

Initially, when I was registered partially sighted, someone did come out to the house but they didn't do anything even though I said I was struggling with some things. But when I was registered severely sight impaired, they started to come out more then. They came out and assessed me and gave me some grips. They gave me those little bubbles that you can feel but I have got no feeling in my hands, so they are of no use to me. I am diabetic that's why. They also gave me a talking clock. That lasted a few weeks and had to buy a new one. They also gave me a talking radio and audio books, and some mats. It's just a little strip that you put on the table. The quality of the equipment given was not good. About six weeks ago they finally put a handrail on the path to our house. They kept telling me that I couldn't have one of those.

It's not the sight loss but how to adapt that is the key issue and give us the things to enable us to live life. For instance, being with people, take your dog out, go for a run.

No systematic process for contacting individuals that have sight impairment difficulties but have not reached the threshold for registration

People told us there is little clarity around how people access support when not yet registered. Some are still receiving treatment to maintain their residual vision and would not necessarily be aware of the council's vision rehabilitation service unless they meet an ECLO⁵ on a hospital visit. The only time they come to the attention of the vision rehabilitation service is when they face a mobility difficulty or have a fall.

I was registered severely sight impaired/blind early 2019 with the ophthalmologist. But I started treatment in December 2015. The doctors didn't want to register me as they were trying to manage my vision with lenses. So I was actually in limbo for two years. It wasn't actually until July 2016 that my GP said 'Oh, have you never been referred to Focus Birmingham?' So, when I came to Focus, they assessed me for low vision and they referred me to rehab. This was because I was nearly run over several times trying to cross the road and a smack in the face from bushes and things.

When those who were not registered did receive the support from the vision rehabilitation team, they found this useful. However, there is a need for a systematic process to identify those that are not yet registered and offer support. Information about the vision rehabilitation service should be made widely available in different settings for people with sight loss including GPs and eye clinics. The routes to contacting the council's vision rehabilitation service for people who haven't met the threshold for registration need to be as clear and consistent as for those with a CVI, and should be built into service planning.

The impact of sight loss and a lack of vision rehabilitation support

People who were not registered and had not had any contact with the rehabilitation team told us about difficulties resulting from their sight loss.

It's getting more difficult to do things like sign a document. The deterioration has been more rapid than I thought it would be. My poor vision impacts my life greatly. I am a keen walker and I would go out every day except for Sunday because that is a family day. And I would get on the bus and I sometimes go to Solihull, Wolverhampton on the Metro, Merry Hill or West Bromwich. I would just go somewhere and would be out for two to three hours. Have a coffee and be amongst other people. But I can't do that now because I can't see signs. That has restricted me. I go down Harborne High Street and if I go in shops, I can't read prices or sell by dates. I can see enough to pick things up and hope for the best. I don't have to do it, I must admit my family are happy to take me shopping and they feel I should ask them more. But it is about my independence. I want to wake up in the morning and say today I will do this.

Recently, I had a terrible fall. I was walking in Harborne, crossing the road and you know those pebbly things that are supposed to help the blind are dangerous. I tripped on them and I went flying over right into the middle of the road. Once I fell over whilst I was with my daughter. I haven't had any support to help me with how to move around safely. I am a very independent person and if I could be helped to move around the community safely then I would maintain my independence.

Without contact with the vision rehabilitation service some people have had to rely on charity organisations or family for support. Most have had to work out what they need and purchase equipment themselves.

I don't see how anyone could really help me anymore. I had a walk-in shower put in and my bath has a seat. I paid for all the adaptations in my house. I thought I will not be able to claim benefits, everything will be self-help. I am used to looking after myself. I didn't think I qualify because of my civil service pension.

I never met a vision rehabilitation officer neither did I have an assessment done. Nobody at all has come to see me

5 Only a few of the people we spoke to had met an ECLO at the hospital. Due to the small number of ECLOs not all people faced with sight loss have the opportunity to meet an ECLO who might signpost them onto the relevant services such as the vision rehabilitation service or a charity organisation. However, this was not the focus of the study.

after I received my card. I didn't get mobility training (i.e. route guide) or daily living skills training. I just get on with it. I do burn a lot of things but I still eat them otherwise I would go without. A friend came and put in some special lighting for me and I bought other equipment from a charity organisation. I do not feel independent or an active member of society because I can't do the things that I used to do.

No-one has come to help me with my daily living skills but I bought some things off a charity organisation. Like there is something you put in your cup when making your tea that can help you know how much milk to put in and so on. I also bought magnifiers, white stick and talking watch off the charity. I am paying for things that others are getting for free because I am not pushy.



Vision rehabilitation assessment - assessment of needs and specialist assessment

CASE STUDY

Mr S is registered blind and has been a guide dog user since the 1990s. However, since May 2019 he has been without a guide dog and has been informed that it will be a year until he receives a new one. Mobility is proving challenging and he relies on friends and family to go out, otherwise he is confined to the house. Mr S knows he needs cane training in order to be independent and says he currently has low confidence. He does not know what the vision rehabilitation service offers and who to contact. Mr S has been on the council's register since the 1990s but never required their support because he had a guide dog. However, he wonders why he has never been contacted to see if his situation has changed.

According to RNIB, individuals should be seen and receive a specialist assessment from someone with appropriate skills, knowledge, training and competency within 28 days following initial contact. Specialist skills are important as they ensure that the unique challenges faced by partially sighted or blind people are identified. Individuals should have a plan in place identifying goals and outcomes based on their assessment. They should also be offered a care assessment when vision rehabilitation does not fully meet their needs or be signposted to information and advice about relevant local organisations.

The main concerns were:

Assessments are directed by the assessor and do not seem comprehensive or focused on the individual and their needs. There is some feeling that assessments were not done by a vision rehabilitation specialist.

I don't think the assessment of my needs was done effectively, there was no paperwork done - that would have been ideal, then I would know what to expect. The thing is when you have sight loss it's difficult, you do feel like life is at the end. Someone with sight loss doesn't even know that being independent is an option anymore. To

me, I think that's what the rehab team should be coming and telling you, that this is an option. It wasn't like that. To be honest, I thought that rehab was just about cane training and when they gave me some equipment, I was like 'Great - a bit of equipment'. But I didn't know until after that, that assessment was not done properly. A proper assessment and informative assessment would make the service better. Inform me on what my options are, on the possibilities. I think that is key. When they are doing the assessments, they need to understand that no vision is the same. There is an A-Z list of eye conditions and that tells you that the world of vision impairment is massive. Someone can see to the side, someone else has tunnel vision...is the assessment assessing this? What are the different routes? An assessment can't be just 'How are you doing?' and a little bit of a nose around my house and that's it. They need to know can I see to the side or am I blind in the dark? There are so many different ways people see.

If they could signpost a bit better, something as simple as Focus will help you do your PIP form is a big thing for someone that has just lost their sight. RNIB do a phone form filling system...if they just pointed that person to them or to the Living with Sight Loss course, that's a massive impact on someone's life. People are suffering in silence because they don't know.

They just basically asked me leading questions like 'You don't have any problems you need assistance with, do you?' That was it, it was very brief. I have had mobility services since but at registration it was a very brief and very leading discussion I felt. There was no real in-depth assessment at all.

Assessment (including the support offered) is geared towards people who are less capable and independent. As a result, some said they found themselves having to overstate or exaggerate their difficulties to ensure that they received support.

I am registered severely sight impaired/blind but have some residual vision and I feel I have to seem incapable in order to access services and support. Whenever I have spoken to the council, I have had to say that I'm in a far worse situation. In order to get a bit of support and understanding I have had to overstate my condition. The fact that I am looked on in a different way to people who have no vision at all, I find that really interesting. Then someone will keep telling you 'Oh no - you can't walk there'. Rehabilitation support is designed for people who are far less competent than most of the blind community are. I don't really know anyone in the blind community who is incompetent in doing things - they just need extra support to get more confidence to continue doing what they are already doing. Otherwise when you say that you can do something, you are told you cannot access that support. However, that support would have made a massive difference to my life.

The council should rephrase their questions when they assess people. They need to say "This seems difficult, what can we do to help you do this?" or "If we put this support in place, how does that work for you?" Rather than saying 'You can't do this' or 'You have a disability so that is impossible'. They should say "This is the task, how do you want to approach it?" If you have not done it before, they can say 'Here are a few examples of how other people have done this task before'. It's being a little more positive about it.

They came out to do an assessment of the home after my sight changed. When I was assessed, they just came and we had a general chat, there was no plan put in place or anything like that. My assessment was with a generic social worker, not a vision rehab specialist. The lady I saw had an interpreter with her as she was deaf. I didn't think they understood the needs of a person with a vision impairment. I don't think anyone can understand the needs of a person with visual impairment unless they experience it. I definitely did not understand the needs until I lost my sight.

The council phoned me and we went through some tick list stuff. They asked me questions like 'Can you do this?' or 'Can you do that?' There was no communication about the outcome of the assessment.

Lack of referral to other services, information or organisations based on assessment of needs, particularly for mental health or welfare support

I don't even get any support from welfare ...no support allowance or anything like that. I'm blind, I need some kind of support.

It was only last September when I was registering for the second time with the council once my CVI changed to blind that an ECLO told me I could get some welfare support.

A good experience of assessment for me would have been a proper discussion about what could help going forward, helping me to understand my sight loss. I don't think that was ever there. It is common knowledge that when you get diagnosed with a degenerative condition, or any sort of condition, that if you don't really understand it there is a lot of anxiety and there is a close correlation between mental health and sight loss. So, someone to address my mental health and anxiety, someone to explain to me where I can get support or what was available. Information and reassurance would have been useful.

Support as outlined in the Care Act would have made my life so much easier and accepting what had happened really. It's a loss and you have to deal with it emotionally. Then you have the physical problem of not being able to see. But if someone had just sat with me and talked about the possibilities then it would have reduced my anxiety. It would have been a better transition if that makes sense.

When I saw someone from the council, the first question was 'What do you want?' The assessment wasn't done in a way that was very nice. It wasn't very professional. To be told you have lost your sight, you need some support there and you need someone to be a bit more sympathetic - not just 'There you go, it's happened, get on with it'.

Some people told us that they had to rely on family members or charity organisations for emotional support.

For my mental health, I had support from my family and someone from a sight loss group really helped me. She made sure that I came to a group and speak to people when I was coming to grips with my sight loss. Coming to a group made me realise that I was very fortunate and I have a lot of support.

Rehabilitation should have included a discussion on mental health. If I had gone to someone and said I was depressed they would have put me in the looney bin. It was my mom that took me out of my stress...it was all left to her to deal with my mental state. My mom fought my corner, she pushed me and asked me to snap out of it. Encouraging me to go out or if we go out and buy shower gel then I put it away myself so I know what it is and where. That's why I am confident today.

Birmingham City Council did not provide mental health support when I registered. I was able to go into one of the sight loss charities and speak on a one-to-one basis and I built a relationship with members of staff there. I was able to go in and express myself because I was new to sight loss and didn't really understand it. No one had explained it to me. The combination of that person and being referred to see a counsellor at another charity organisation - that made such a difference. The major issue at the moment is that I have had friends who have committed suicide due to sight loss and others who have been at the edge of it. I have been through that mindset myself. But I think that the big thing I found is that I was able to speak to somebody face-to-face and express how I feel. Rather than someone just telling you 'You do this and do that and you will be more independent'. It's not purely the physical, learning to do everything, going back over that. Relearning stuff is important but you need to be able to express yourself, and process that emotion because it is a whole grief cycle. It's like losing a family member because you have lost a part of yourself.

After diagnosis I went through a mental breakdown and had to battle it out myself. My family lives very far and I had no one. Even at the hospital, there was no one to support me or guide me to the information I needed. Joining a sight loss group is the best thing I ever did because it saved my sanity.

Most people we spoke to argued that, because it affects your whole life, the council should have a holistic approach to sight loss.

They should be looking at the wellbeing aspect of sight loss, the resource, adaptations aspect of it, looking at the

network aspect of it – what is out there. Give an overall assessment, not just say ‘We have been to see you and we have told you to get in touch with these organisations’. Because if those organisations don’t exist any longer or do not provide services because of lack of resources what is the point in just having a paper exercise? It’s about having a properly resourced service, and having a holistic assessment.

Receiving vision rehabilitation support – in-depth rehabilitation

CASE STUDY

Ms L is registered blind. After receiving her CVI she says she had to chase the council to register, and then had to wait for the vision rehabilitation officers to carry out an assessment. Ms L was also suffering other health issues, such as problems with her back and kidneys, and says it took her a long time to come to terms with her sight loss. As a result, she could not keep up with mobility training. She compares the support she received from the council with that she has received from charity organisations. Ms L finds the training received from the charity sector less regimented, more flexible and more relaxed.

The Care Act states that rehabilitation support following an assessment should be provided by a professional with relevant experience and training. Rehabilitation should be provided beyond the six weeks prescribed for other forms of rehabilitation to take into account the distinct nature of sight loss. Therefore, people should be given adequate time to learn new skills and have their needs met. The council cannot rely on their information and advice services to fulfil their duty to prevent, delay and reduce needs. This is separate to any other duty in the Care Act.

The main concerns were:

Lack of clarity about who is responsible for or who to contact about different aspects of rehabilitation, and no direct contact with a specialist team

I was given a number to contact the council when I needed help. I called that number but they said they had no idea that there was a blind register so they kept swapping me between services and I ended up with nothing. So, I’m comparing this situation to when I was first registered, when there was a whole department at Duchess Road⁶. A department with at least four or five members of staff who were trained as vision rehab officers and they had kitchens there. They had a whole set up designed to do rehab. That was closed down and it shifted to Ladypool Road and Ladypool Road became generic. As far as I’m aware, the council does not have a proper team of trained rehab officers.

The council used to have a guy at Duchess Road who helped me with the cane and supported me in using gadgets. They also signposted me to RNIB, guide dogs and so on. That used to be good.

There was a lack of understanding between occupational therapy and rehab about who was responsible for what. I had to go back and forth between the two and I basically had to find out myself about my entitlement to a disability allowance that I might be entitled to for instance.

Support is hurried and not enough time is given to learn the skills necessary to be independent. Some found the support inflexible and some felt they did not receive the support for as long as they needed it.

The rehab the council give you should not last six weeks as this is not enough. They should look at this on a case by case basis. Understanding what people’s needs are. One person might take two months to do the training. for

6 Duchess Road (near Five Ways in Edgbaston) is where Birmingham City Council had a Rehabilitation Unit for people who were having practical difficulties due to their sight problems. The unit provided training in daily living and communication skills such as typewriting, handwriting and Braille. People who are experiencing difficulties with moving about safely as a result of sight loss could also benefit from mobility training.

instance to get them walking from one street to the next and be safe. But others might be different because their learning abilities are different or they have a disability. You can't paint everyone with the same brush.

I was not expecting the rehab support so it was nice when something came. But then it suddenly finished. But I appreciated the work he had done. I mean he wrote a lengthy report whilst he was here. The problem I had is that they had nothing upfront that told you what happens when you register. It was a big learning curve.

A combination of vision impairment, mental health and other conditions made it challenging for some to keep up with the rehabilitation support.

At the time that I received my mobility training I had been diagnosed with depression and anxiety because I had had a number of falls. I was also anxious about going back to work.

Support does not meet people's needs after assessment. Some people indicated they received items that they do not need or could not use.

Some said they were not given options in terms of the rehabilitation support they could get.

So, rehab came and had a quick look around my house, threw a few things at me, gave me some cane training and then off you go. For me I am light dependant and apparently the rehab can give you a task lamp. That would have been absolutely ideal for me. To be able to cook and chop things. Didn't even know that was an option. That was never even asked and it was never mentioned. They gave me some writing frames, a watch and they did some training. The training was very brief. They came twice and we did a bit of down the road walking. I did catch on to it quite quick. We did cross the road that was it really.

We did do an assessment and it was written down somewhere. But they took it with them so we never had a copy of it. They wrote down that they had given me a watch and a clock, things like that. But when I asked for things, they kept saying 'Oh no, you can't have that'. They didn't really assess what my needs are or provide things according to that need. They only wrote down what they could provide.

I was only offered white cane training and that's it. Unless you go to Focus Birmingham or RNIB there isn't much out there for blind people.

Some found that the location of mobility training did not meet their needs.

The six weeks mobility support was done very locally and I think I would have been happier if we went to other areas that were not just around my house. Places that I normally visit.

The guys at vision rehab are good but they don't understand. The first time I did mobility training was around the university hub. That's not going to help me in the real world. When the second time came to do my bus training, I said to them 'No I'm not doing the bus training unless it's in my area'. I said 'I don't want to be walking around the university or the park - it's no use to me.' That's when she came to my house and we did it. I live in a communal area and before I wouldn't even walk to my neighbour. To be fair, she broke the training down to segments and so to this day I know where am going. If there was a fire, I know how to get out of my house now. She taught me how to get out of my place down the steps to safety. That was the good thing about the council rehab.

Lack of signposting to information, advice and complementary support

The only thing with these things is that they say 'Would you like better lighting in here?' and I know I want some different bulbs in the landing and the hall to help me down the stairs. But nobody tells you where you can get these things from. When I wanted a telephone number, he said 'Oh Focus will know the number' and I thought, 'He should know that'. So, I don't know where you go if you want to ask questions from the council. I said to him 'What happens if I want some advice, do I phone you?' and he just gave me a number. It felt a bit unfinished. His

work ethic was terrific. He had been to seven calls that day before he came to see us.

Give people enough information to make an informed choice. Some of the equipment that I saw them sometimes bring out just wasn't an option. OK - they give me a writing frame, just show me a couple of pens. I didn't know there were these pens I could use and thicker lined paper. It's no use giving me a writing frame if I don't know the other things I need in order to use it.

I remember getting quite anxious about forgetting what I was doing and asked if there was anywhere I could go to find out more about it from time to time on what I was doing. I think because of the anxiety and depression I couldn't remember what I had done or what I was covering. There was not really any support in between or signposting to information. Eventually when I did complete the training and I tried to do it by myself, I wasn't able to do it. So, I just ended up leaving it.



Post vision rehabilitation support - follow-up assessments and reviews

CASE STUDY

Ms S is blind in one eye and severely short sighted in the other. She was registered blind in 2019. She says following registration, the vision rehabilitation team did visit her but feels the assessment was not effective and as a result the support she received did not really address her needs. She says that a more informative assessment would make the service better. Ms S also thinks that the vision rehabilitation service should improve at signposting people to information and other organisations.

Follow-up reviews of individuals that have received support have been identified by RNIB as a key stage in vision rehabilitation. RNIB argues that when a plan for support has been put in place following an assessment, it should include an agreed timeframe for review. Most people we spoke to told us about challenges trying to access further support from the vision rehabilitation service when faced with difficulties or their sight changes. In particular, those who had been registered for a long time and had already accessed rehabilitation support were unaware that they could re-refer to the service and who to contact should for further support.

The main concerns were:

People did not have follow-up assessments or review dates built into their support plan, nor were any reviews carried out. For those that received further support such as mobility training, an assessment was only carried out when the individual had difficulties such as a fall.

The nature of sight loss is varied and this can impact how people engage with vision rehabilitation support. The different ways individuals react to losing their sight can also lead to depression and anxiety. Therefore, some might find certain tasks more difficult or take longer to learn new skills, and find they need further support.

You might find that in three or four years' time you might need more training in this or that. Also, when you first get diagnosed and then registered, you're going through that grief process and you are learning to function in that way so it is difficult to process support. But in six months' time you might be a completely different person and you might think 'Actually can I go back and do that support again because I wasn't able to at the beginning?' In fact there are a lot of things that I was provided with when I first registered that I realised six months or a year later that I would really like to go through again, because I was going through the grief process and I wasn't able to fully respond to that or engage with that. You might find that a few years down the line you could use that support or if you move areas.

The length of the initial vision rehabilitation support was often not sufficient. This led to people feeling less independent and secure as well as needing further rehabilitation support.

I had a little bit of mobility training from the college and city council. I think I need another mobility assessment. Mobility sessions were only six weeks and once six weeks was done you have to do it with the support workers. This is not useful. I am not allowed to do anything and can't step out of the house because they say 'Health and safety'. They worry about the steps and me crossing the road. If I had mobility training, I would have more independence and security.

I was born blind so I have only ever had carers from the council. I have never had training to move around by myself without a carer. I would like to have had a review because I started training for a guide dog but my wife said she could not take care of a dog as she also looks after my parents. Because I have not had mobility or daily living skills training my family does not allow me to do anything. I would love to have more support with my mobility, living skills and so on, because sometimes I get hacked off with the family.

Most were not aware that they could re-refer themselves to the vision rehabilitation service

It wasn't until I went to the Living With Sight Loss training and someone from the vision rehabilitation service came to speak to us that I found out you can re-refer to the council for more support. He seemed better because he seemed to know about the different kinds of sight loss conditions, and that dependent on your sight condition that would influence when you are able to confidently use the cane.

No single point of contact means people do not know who to call for different concerns

The support I received at the time was lovely but after that, the support evaporated. After I had had a little bit of rehabilitation ...I had gone through cooking and a bit of walking. Then it was really difficult to find the support again. I was told I needed cane training and it took me weeks to get in contact with people. It was very stressful trying to contact the council's vision support team because you don't know who to contact.

My main challenge has been the follow-on support from the vision rehab team, especially getting the right person to contact when I need more support.



What would improve people's experiences of accessing vision rehabilitation services?

Clarity about how and who to contact for support

My idea of good care would be someone to give you a sheet of paper after you are diagnosed with just one number and somebody at the end of the line who understands what you are going through. My experience after being diagnosed was negative. After I was told that I will lose my sight, the doctor just told me to accept what has happened and move on with my life. I was left with that in a taxi on the way home. I live on my own and I got to my house and slipped down the wall and dropped to the floor in tears. It was left to me to pull myself together.

A good experience would have been when you go into the doctors and he says 'By the way - you are blind' then sends me to see someone to discuss with you what's happening with you and explains your options or services available to you. Then give the person time to let it sink in and give them contacts to contact someone when they are ready or contact them after a month. Then get them moving because you start thinking your life is over.

Clarity about the registration process and referral routes into the vision rehabilitation service

We are focused on the CVI thing. This is great but consultants don't want to register us - that's not a bad thing because they want to exhaust all the options. So, in my case it was two to three years. It was in 2015 I got diagnosed but only in 2019 that I got registered, so he did exhaust his options. So, from the end of 2015 and if we say support only comes after I'm registered in 2019, then I'm in limbo. The clinic nurse should be able to refer people like me to the rehab team at that time when we are not officially registered...it would take two minutes.

Support that helps individuals to live as independently as possible

Vision rehabilitation support would have been brilliant. Delivered in the way that helps you to meet your needs would have been useful because without it you have to work out things yourself, like how to not overfill the kettle. Because you don't know what you can't do until you come to do it. Picking out clothes from my wardrobe...I only have dark bottoms and lighter tops - that's it - they match. I don't have to think what colour things are. So, you do work things out yourself but it would have been so useful for somebody to tell you that before you experience it because your anxiety levels would reduce. You wouldn't worry that you broke the kettle because there was no

water in it or you put conditioner in your hair instead of shampoo. Just basic everyday things and have someone you could tap information from. If you can have that built into my plan, and review it often. Someone can talk to me, even if it's just a sit down over a cup of coffee to discuss with me things that other people have found useful, see if they help you. These are the things that make your life normal. I don't want to be Ms W the blind girl. I just want to be Ms W. So, help me be as normal as I possibly can. Yes, I have a massive stick in front of me but apart from that I am still me.

Better and more accessible information and advice

There should be a crib sheet of things one might encounter once you lose your sight.

An issue is getting information that you need. Someone needs to be there in the hospital with the right information because when you are told that you are blind it's like a kick in the teeth. You have gone through life not thinking you could lose your sight. Someone needs to be at that hospital. It seems that in the hospital they just get you in and make their diagnosis and they are done. They want you to find the information yourself. That's alright for some people, like I had my mom and went out and found the information we needed to register with the council. But some people are not like that. You need someone in the hospital. Things that I have found is that, until you know what's out there, then you can access services.

What I did find useful is that they sent out a few fact sheets with what services you could access. So, I rang RNIB and they sent out a very useful booklet with information about all the things you are entitled to in different situations including rehab. That was very clear.

Switchboard at the council need to be made aware that there is a blind register.

A generalised standard tick list so everyone knows what they can expect and what is available to them. I would say that's a big thing. It would be useful if the rehab team sat down with people who have sight loss, different conditions of sight loss and develop a tool about what is available and what can be expected. This would be a great tool only if the service is actually given. This would mean getting the NHS involved.

Comprehensive assessment and support that addresses various aspects from an individual's eye health to emotional, physical, financial and social needs

There has got to be some mental health support. It is a life changing thing, it's a loss. I am 52 in May and feel very isolated. My partner died 14 years ago from cancer, my father lives in Spain and we lost my mother five years ago. I have nobody. People think it's only elderly people that do not have anybody but there are activities on the other side of Birmingham that I cannot get to.

When you lose your sight, it is emotionally challenging as well as all the other stuff. Assessment should not only be about your physical challenges, they should also assess your ability to cope with sight loss, live with it and your personal circumstances.

It's also about the basics as well. When rehab officers are in the house, can't they also just tell you about audio descriptions on the TV? It would take them like two minutes to tell someone that. I think for me, rehab has great potential but if they are going to go in and help people then also look at the basics. 'Do you watch TV a lot? Here is an audio description and here are some bump-ons for your remote'. For me for the first few years, I stopped watching TV, so even if people came to my house and they were watching TV I was a bit antisocial because I could not get involved. Now with audio descriptions I can interact with family. When the TV says 'She falls off the stairs' I'm involved in what they are watching. It's making me social again but that's just a basic thing. They could even just refer to the Living with Sight Loss group.

More follow-up calls and reviews

People need to be called, they need to be reviewed every now and again. Birmingham City Council have forgotten about me.

People need reviews so that they are not forgotten when their sight deteriorates.

I got diagnosed pre-Care Act. Need a regular review of service users including those that haven't been assessed prior to the Care Act. To have a look at those on the register and have a holistic review of their case. And not just everybody that is on the register, but actually encourage people that are not on the register. There are many people that are not on the register and don't know what to expect when they are on the register.

Better co-ordination of services

There needs to be more joined-up working between social workers and doctors and rehabilitation specialists. The specialists know which eye condition will potentially lead to blindness. There needs to be more information between these three professions so that they can co-ordinate the whole system better. More proper and meaningful working together not just joined-up but something that actually creates a proper working system.

I think there need to be better facilities for people who have lost their sight. Then there should be better connection between the services. I think lots of people will tell you that they go to the hospital and yes, they diagnose and yes, it is macular and they sign you off saying 'We can't do anything'. So, then you are off and you are left a little bit in limbo. It was only when a friend referred me to Focus otherwise, I would be in great deal of difficulty. I can appreciate that the hospital can't do anything about it but it seems rather a drastic step to say 'We can't do anything' after diagnosis.

Clarity about how to access vision rehabilitation in the future if required. In addition, the process, including further assessments, should be simplified and less rigid.

I just can't ring the council up and say 'I'm really nervous about going outside - can I have someone to support me because it's really difficult?' I would have to say 'When I went outside last week, I tripped over this and that three times' in order to get that support. That wasn't very helpful. For me if I get this kind of barrier and I know that there is support I can have to make my life better, I will fight and push. But there are other people who cannot do that and they would have just gone like 'That's not for me'. Then you've got people being isolated because they are not going outside and this leads to depression and suicidal tendencies.

When I first got registered someone did ring up and asked if we would like someone to come and see me and I didn't feel like I needed someone at that point. They did leave an open channel for me to get in touch with them when I was ready. Last September when my eyesight worsened, I did contact the vision rehabilitation team again. Someone came and he watched what I was doing with the cane to make best use of it. Another time we went outside in the street. He then suggested one or two things. He also came into my kitchen and gave me a lamp and a clock.

A standalone vision rehabilitation service providing direct access to vision rehabilitation officers

They should have a rehabilitation unit, as they used to have, with just rehab workers for vision impairment. Also, a part of social services that deals with vision rehabilitation only. You shouldn't have to go through all these call centres that deal with a whole host of issues from blue badges, occupational therapists and go through all these conditions they place on people. What they have done is mix the whole thing up to cut costs. When actually there should be a resource base where people with vision impairment can go and learn.

The main thing that would make a difference in my life and others with a vision impairment is direct access to the rehabilitation team. Cut out the middle man. People don't know whether they are talking to rehab officers. They are not given the information they need to know their rights. Someone like me who has been through the system and knows my rights struggles so can you imagine people who have just gone blind? It's a dramatic change in someone's life.

The gold standard would be a place where specialist facilities were available. For instance, adapted kitchens, IT stuff that people could experiment with or get training on and mobility assistance – long cane. I have had time to get pieces and understanding of the conditions and get the necessary skills. Whereas if someone is clobbered with age related sight loss, they need assistance. If they are going to make a difference to people's life, they need to have a scaled down version of Duchess Road. If they are to provide anything that will be of use to people this is the best solution.

Receive an assessment and support from a specialist with appropriate skills, knowledge, training and qualifications

What would make the rehab service better is not generic social workers but trained vision rehab specialists. It's not rocket science to provide vision rehab, but unless you know what you are doing, you can give completely the wrong advice to people. That's why specialists are important.

A better resourced service

A properly funded service should be their priority. There is no use in saying 'This is what is available' and then not following up.

The facilitators of good access to rehab services is - for starters - they need to have more rehab officers in post.

At the end of the day what you are doing I think will be useful to people but without the funding nothing will come of it and we are back to the old thing.

More awareness of the support on offer

What would be important is having knowledge of what the council can provide. There are many other ways of putting this information over or sharing information through memory sticks.

A good experience would have been at the point of diagnosis and registration to have somebody to come and have a discussion with me to say what is out there, what is available and what I might find useful in the future. I shouldn't feel like a burden or a nuisance, so some reassurance really about what was there and what support services were there.

I do think there is a lot more that mobility teams could do. There is a lot more in terms of knowledge. In terms of providing both a physical and mental assessment and support. People have to be ready for support and know how they are going to help.

Access to technology to aid independence

I would benefit from access to technology equipment to stay independent. Currently the equipment is very expensive, especially when most blind people are on benefits. Half of us can never afford this equipment without saving up for six months to a year.

The council can include app training such as Google Maps in addition to the cane training to their mobility training.

Appendix 1

Birmingham City Council vision rehabilitation team response

To begin our response we feel it is important to define the different teams and the different professionals within them as the paper does not provide this clarity which leads to confusion as to which service is being referred to or at what point in the citizens journey is being highlighted.

Sensory Impairment Team which is responsible for managing and maintaining the registrations of blind and partially sighted registrations. Also, conversations in line with Care Act 2014. This team is made up of qualified Social Workers who also have the qualification stipulated in the Care Act 2014 regarding dual sensory loss assessments.

Visual Impairment Rehabilitation Team consists of qualified Rehabilitation Workers for Visual Impairment (RWVI).

From the start of Healthwatch's research, we have been keen to hear the feedback from citizens including how they have found an experience with our service areas. We have requested for permission to be gained from those involved in the study so that the input provided by BCC can be confirmed to Healthwatch in order for a balanced overview to be provided, to date this permission is outstanding and we anticipate that once received will form part of the six month review of the service. We highly value the opportunity to hear from individuals and the time they have taken out of their lives to provide us with views both via this study and with feedback provided directly to our service areas. We are committed to developing Visual Impairment Rehabilitation services. We have, as part of an ongoing process, being reviewing our service areas.

We can confirm that in 2018 following a concern raised in relation to waiting times to access the Birmingham City Council Visual Impairment service, a review of the service function was undertaken. This review highlighted several areas of development work some of which have been undertaken already and others remain in progress. As with all public services, there remains a requirement to continually review and appraise services to ensure that the needs of the community being served are met, as well as incorporating the use of new methods and technology. Since the work conducted by BCC in 2018, we can confirm:

A review of the whole registration process was conducted to ensure that Birmingham City Council's formats of communication including correspondence and factsheets were developed and are fully accessible and fit for purpose in order to ensure the highest level of engagement with visually impaired citizens.



A review of Visual Impairment services took place which resulted in the following:

- A single point of access to visual impairment rehabilitation.
- Review of the rehabilitation service delivery and role of the rehabilitation officer resulted in increased capacity to provide face to face intervention and consequently resulted in a 40% reduction in waiting time for rehabilitation.
- Members of the Sensory Impairment and VI Rehabilitation teams also engaged and continue to do so with third party agencies.
- We have also attended a forum to which citizens with visual impairment were invited to provide us with their experience of using the service. This provided us the opportunity to obtain views of the services in general as well as being able to respond to individuals' own situations and support them in resolving any outstanding issues or unmet needs.
- We have continued our commitment to attend the Visual Impairment Partnership Consortium meetings which occurs quarterly.
- We also attend all meetings for the Local Eye Health Network as well as subgroups looking at the development of services for example the ECLO provision.
- Joint working with charity organisations which has resulted in BCC including their leaflets and service delivery information being sent to citizens as part of their registration resource pack.
- CVIs are now received by the Sensory Impairment team. This has reduced waiting time significantly. Presently there is no waiting list within the Sensory Impairment team.
- We have frequent two-way communication with Eye Clinic Liaison Officers (ECLO) and with the development of this service across all hospitals in Birmingham provides us with the opportunity to explore the joint up services to promote the citizen's journey. As part of this service we aim to give serious consideration and commitment to provide a presence within the eye clinics.

As of March 2020 Birmingham City Council have commissioned three Information Advice & Guidance (IAG) services with the aim of providing a single point of access to services and information. As set out in the Care Act 2014 the aim here is to maximise the possibility to delay or prevent the need for statutory intervention. One of the IAGs is specifically for the visually impaired community of Birmingham with the Sensory Impairment team working closely to develop and establish a streamlined service which provides the citizen with an efficient and fluid journey through the service area.

We acknowledge that it can be difficult for citizens to navigate the adult access point routing through to the Sensory Impairment team and Visual Rehabilitation Impairment team. In response to this in 2019 the Sensory Impairment team developed an inbox, to which, all professionals from hospital Ophthalmology departments in Birmingham including Low Vision clinics can refer directly this includes citizens who have recently had their sight loss registered as well as anyone who is not certified or pre-registration who they may have concerns about.

For many who experience sight loss, their first contact with specialist professionals can come from opticians, Ophthalmology departments and ECLOs who are involved at the point when it is confirmed that they have a medical issue with their sight. We feel that the role of those involved earlier in someone's sight loss journey is vital in helping citizens to understand what is happening and where to go for support. The Failing Sight Leaflet had been co-produced by health and sight loss professionals as well as with specialist charities and ourselves as a tool to help people to be aware of where they can go for aspects of support and daily living. This leaflet has been disseminated to all citizens as part of the registration pack as well as being provided if needed during contact with social workers. We acknowledge that this requires updating and taking this forward we will develop a similar information resource as part of our action plan in response to this report.

It is important to point out that the support required for someone who is partially sighted can be significantly different to someone who is registered blind due to their functioning residual sight. This would therefore impact on their eligible needs and therefore the support identified. This may be one contributing factor why citizens felt there was a difference in contact and interventions however the individual eye condition and situation would be significant factors also.

We recognise that increasing the service profile directly with citizens and their carers is important. Additionally, further development is already underway to expand the use of Neighbourhood Network Scheme and increase the availability and access of advice and support to those with a visual impairment in the community.

As we have learned from feedback we received in 2018 and the Healthwatch report, there are some continued

difficulties for citizens to orientate between service areas, in response we produced a clear process map which we presented to and circulated with multiple specialist sight loss charities circa May 2018. Whilst it may still be difficult for citizens to interpret services as we are a large and complex organisation, it is our intention that their understanding of how the services are designed is not a prerequisite or barrier to their access of the services – we have a one-stop contact centre available 0121 303 1234 / ACAP@birmingham.gov.uk as well as referral options via our website. Where referrals are made by citizens, their friends, organisations or others; referrers just need to express their concerns and requests - it is the role of Contact Centre Officers to identify which service area(s) are appropriate and ensure that the details are brought to the attention of the Sensory Impairment and/or Visual Rehabilitation Impairment teams, as well as other applicable areas such as Occupational Therapy and also signposting to external agencies if appropriate. We would encourage charities and health professionals to ensure citizens are aware of how to refer into our service and to continue to provide support to do so. We are able to confirm that there is no criteria in place for citizens to access support from the Visual Impairment Rehabilitation service and often people are provided with an assessment on request, often assessments are provided for those who are not Registered as having sight loss and without having a diagnosis. We continue to welcome all citizens who feel they would benefit from visual impairment rehabilitation support to make contact whichever stage of their sight loss journey they are on and other Social Care needs to make contact via the above contact details.

We would like to thank citizens who have shared their experiences through this research again and encourage all you or carers with individual concerns such as those included within Healthwatch's report to please contact our service as we would like to understand your concerns as well as to work with you to further explore any support that may be relevant to you at this time. Our goal is that every person would be aware of our services, be able to access these and have a positive experience of the service areas.

We have been made aware by Healthwatch that there was positive feedback regarding citizen experience of Visual Impairment Rehabilitation provided to them through their research however we note that this has not been included within this report which is focussed on what the challenges and barriers are experienced; we appreciate acknowledgment that the lead reporter raised that a "harsh" interpretation had been provided in areas.

Birmingham City Council, Sensory impairment team currently forwards a post card to every citizen who we have contact with whether this be face to face, visit or telephone conversation.

Between July 2018 to May 2020 from the responses received:

- 100% of citizens confirmed they received the information that they needed.
- 100% confirmed that their views were heard
- 95% responded that they understood and knew what would happen next
- 100% confirmed they were treated with respect.

Customer satisfaction recorded by the rehabilitation side of the team confirmed:

- 92% had a positive experience when being referred to the service.
- 100% of citizens understood the purpose and remit of the service being provided and confirmed it met their expectations.
- 97% confirmed that their assessment was conducted in a polite and courteous manner and with respect.
- 100% confirmed they were involved in the assessment process and were able to voice their priorities and any concerns that they had. 100% confirmed that their priorities and areas of concerns were addressed.
- 87% confirmed that they were made aware of how to contact other relevant agencies.

Case study

Conversation 1 completed with Mr G who advised that he is registered blind and had struggled with alcoholism. Mr G initially got in contact because he wanted some support with housing. He was living in a shared accommodation and found that it did not meet his sight loss needs. In discussion, he reported some difficulties with identifying water temperatures, cleaning tasks and meal preparation. In addition, he expressed his desire to return into education however, reported difficulties with form filling and paperwork. Mr G expressed an interest in accessing social activities and groups as well as counselling services. He expressed that his main concern is in relation to his

housing situation (lives in shared housing) and he expressed a desire to relocate as soon as possible. As a result, referrals were made to external agencies as well as the VI Rehabilitation Team. He eventually was temporarily rehoused and recently made contact to advise he has been offered permanent accommodation through one of the agencies he was signposted to. Mr G went on to say he has been grateful for the support received and that his emotional wellbeing/confidence and esteem has been boosted. He advised he had a pleasant experience working social worker and rehabilitation officer and was very grateful for the support. He stated received beneficial intervention from the VI Rehabilitation Team who sent him some equipment to support with kitchen safety etc. He remains in contact with all the agencies he was signposted to and has reported to be feeling more positive / cheerful.

Action plan

In response to the Healthwatch report we have taken on board the experiences shared by the citizens and have identified the following targets which we are committed to developing and achieving as part of the growth and improvements of our service delivery. This will be reviewed as part of the Healthwatch six month review following publication.

- Visual Impairment Rehabilitation officers will be adopting the 3 Conversation model to ensure our interventions remain person centred and strength based, exploring the needs of our citizens holistically with a focus on how their sight loss and possible dual sensory loss impacts upon their daily living. We are already in the process of adapting our paperwork. <http://partners4change.co.uk/the-three-conversations/>
- As part of the 3 Conversation model we will be reviewing the sight loss journey for our citizens to include a review of interventions provided to them as well as provision of conversation assessment documents in accessible and preferred formats.
- We have commenced recruitment process for an additional Visual Impairment Rehabilitation Officer.
- We will deliver sight loss awareness training to contact centre staff who will be the first responders to citizens and professionals contacting BCC for referrals and queries.
- Following certification citizens are contacted within 2 weeks however we acknowledge that this is currently via correspondence and so we will explore possibilities of developing this into a more personal and direct form of contact.
- We will work with the appropriate colleagues to improve information available on our BCC website, accessibility and ease of use and navigation.
- We are already working closely in partnership with Focus and RNIB and will continue to develop referral pathways and the provision of the IAG Service and Living with Sight Loss Courses to maximise a fluid and positive journey for our citizens.
- We are currently revising and updating all our factsheets which are sent out to all citizens registered and will make them accessible for relevant professionals including ECLOs, Low Vision Clinics and sight loss organisations. We will also utilise these in the promotion of our services to GPs, specialists and generic agencies and networks.
- We will develop an additional information leaflet which sets out local and national Sensory Impairment services and organisations with contact details in accessible format of large print.
- We will explore possibilities to have physical presence in attendance in appropriate hubs and venues starting alongside ECLOs in hospitals including Low Vision clinics.

The following points we have identified will commence with immediate effect. However, we recognise that a more realistic timescales for achieving these will be 12 months.

- The Visual Impairment IAG Service contract includes sight loss awareness training for professionals which we will continue to participate in.
- We will explore systems and processes of how the most beneficial way is to maintain contact with citizens on the register.
- We have commenced an overall review of the service and the future structure of the Visual Impairment Rehabilitation and Sensory Impairment teams.
- We would be hopeful to explore with 3rd sector sight loss organisations attendance at their hubs as well as resource centre based at a BCC accessible building.

Appendix 2

Case studies

Mrs MB received a CVI about 18 months ago. At the hospital she was given a form to complete, which she sent to the council but was asked to complete another form as she had moved house. With the help of her daughter she completed an online form eight months ago but has not received her registration from the council. She feels that the kind of support provided by the vision rehabilitation team would have been useful and helpful in ensuring that her house is safe and learning how to do things she has always done in a different way. She has therefore changed the lighting in her house with the help of her son-in-law. She no longer trusts herself to cross the road safely so takes taxis to a point that won't involve crossing the road. Otherwise, she has to rely on others to take her out and would really like to be independent.

Mrs G has been registered sight impaired/partially sighted for the past three years and was registered with Birmingham City Council a year later. After registration she indicates that she never had any direct contact with the council. In fact, she feels like the yellow card she carries is of no use. Mrs G says ***"this card I carry it with me all the time but I have never been asked for it or used it for anything. It's just been lying in my purse. I don't know if there are any advantages of having the card, for instance help me to do anything, I don't know. I don't remember having any info with it at all. I have not received any information at all from Birmingham City Council. I received all my rehabilitation support through a charity organisation"***. Mrs G says through the instigation of the charity organisation, someone from the council rehabilitation team visited her and put grab rails outside her house, widened her steps and put rails up the stairs. No-one from the council came to see what she needed after this. Mrs G has noticed that her eye sight has deteriorated over the past three years. She is finding it more and more difficult to do day-to-day things, including shopping, as she can barely see what is on the shelves and struggles when she goes out as she cannot see the numbers on the bus. Although she goes for frequent checks at the hospital, she still has not had any contact from Birmingham City Council or any reviews of her condition. Mrs G understands that she cannot change her condition but is very determined to do everything by herself. She would like to remain as independent as possible and believes she could achieve this if she received support from vision rehabilitation services.

Mrs B is registered severely sight impaired/blind. However, for the past 10 years she was registered partially sight impaired. She says that it was only after she became registered as blind that the council offered sufficient support. She says she was asked if she wanted help and she agreed because she could no longer drive, cook or safely move around. The council gave her a form to fill as they said they needed to check what she was able to do, and she told them that she could not complete the form as she couldn't see. She was also sent an independence allowance form which she also could not complete. The council then sent someone to complete the form with her. After completing the form, she was asked if she had anything to say, and she told the person about her problems with cooking and other things she used to do. Following the assessment, she received a long letter identifying how difficult it was for her to be in the house and complete various tasks. Soon after, she received support that enabled her to get a carer to help her with daily living activities such as cleaning and cooking.

Mrs B does not think that the people that came to assess her understood sight loss. She notes that they understood that she was blind. However, she says ***"I don't think they took down enough information to really understand the issues I was facing. For instance, the person who came asked me if I was still driving and I thought 'Hang on...how can someone think I am still driving when I am registered blind?' You can't understand something if you have not lived it. It took a fair bit of work from me saying I need help, which is a bit difficult for me to admit. I don't want to be dependent. It's difficult when you think you are going to lose that independence. I have reached a stage where I do know I need help. I cannot use the computer anymore where I used to have my shopping list, I can't read the numbers on my debit card, and I am so frightened of falling that I haven't been out for the past six weeks"***.

Ms K was registered sight impaired in 2009. She recalls that the hospital contacted the council after she was registered. Following which, she received a brief call from the vision rehabilitation service. She says ***"they just basically asked me leading questions like 'You don't have any problems you need assistance with, do you?'. That was it, it was very brief. I have had mobility services since but at registration it was a very brief and very leading discussion I felt. There was no real in-depth assessment at all"***. It seemed to Ms K that the person she spoke to, although a specialist, was gate keeping and going through the assessment as an administrative discussion rather

than with a focus on her needs. She says that a year ago she referred herself back to the vision rehabilitation team as she was waiting for a guide dog. Ms K says that the nature of assessment was the same as she had had in 2009 and it took a long time for someone to carry out the assessment. They kept sending her to other organisations that could not provide her with the mobility training she needed. She says that following a number of falls, she eventually received a mobility assessment. ***"I was really quite anxious and depressed at the time and I was calling them a lot. So, I eventually got somebody who did come out and basically just said six sessions. I kind of felt that because I was partially sighted and not severely sighted or blind, it wasn't considered to be that serious. So, she did give me six sessions and there wasn't anything in writing just the six sessions"***.

Regarding the second assessment, Ms K says ***"again it was a bit of an assessment but still more like I have got this stuff, do you need these things?" and then I would say 'Yes that's useful because I have heard of them from the Living with Sight Loss group or you might need this 'Oh yes yes, that looks useful'. It wasn't like 'Let's understand your needs' and then based on that discussion, 'Here is what we think you need'. Nothing like that. I was grateful for the things I received but it didn't seem like an individual thing. So, I don't really feel like I have had person centred assessment or help. Don't get me wrong, I have had some support but I feel that I had to either look for stuff myself and request these or fight for them. There are things available but when you try and access them, then you are waiting for a long time or they don't fit it in because of staff shortages or timetables"***.

Ms S is blind in one eye and severely short sighted in the other. She was registered blind in 2019. She says following registration, the vision rehabilitation team did visit her but says the assessment ***"is rubbish, it needs to change so that they can get information, educate the person and inform the person. And then put the right things in place based on that person's needs"***. She felt that the assessment was not effective and as a result the support she received did not really address her needs. ***"I don't think the assessment of my needs was done effectively, there was no paperwork done - that would have been ideal, then I would know what to expect. The thing is when you have sight loss it's difficult, you do feel like life is at the end. Someone with sight loss doesn't even know that being independent is an option anymore. To me, I think that's what the rehab team should be coming and telling you, that this is an option. It wasn't like that. To be honest, I thought that rehab was just about cane training and when they gave me some equipment, I was like 'Great a bit of equipment'. But I didn't know until after that, that assessment was not done properly"***.

She feels that ***"a proper assessment and informative assessment would make the service better. Inform me on what my options are, on the possibilities. I think that is key. When they are doing the assessments, they need to understand that no vision is the same. There is an A-Z list of eye conditions and that tells you that the world of vision impairment is massive. Someone can see to the side, someone else has tunnel vision...is the assessment assessing this? What are the different routes? An assessment can't be just how are you doing and a little bit of a nose around my house and that's it. They need to know can I see to the side or am I blind in the dark? There are so many different ways people see"***.

She thinks that the vision rehabilitation service should improve at signposting people to information and other organisations. She says ***"if they could signpost a bit better, something as simple as Focus will help you do your PIP form is a big thing for someone that has just lost their sight. RNIB do a phone form filling system...if they just pointed that person to them or to the living with sight loss course, that's a massive impact on someone's life. People are suffering in silence because they don't know"***.

Mr M was born blind and registered in 1999. He had contact with the vision rehabilitation team in 2001 and registered with the council. They carried out an assessment and provided him with cane training, learning routes and daily living skills. He found the training very useful and built up his confidence. His most recent contact with the vision rehabilitation team was last year (2019) through occupational therapy as he had requested a ramp to replace the steps that were compromising his safety. An occupational therapist and vision rehabilitation officer visited him, assessed the situation, gave him some cane skills in the back garden, and made recommendations to the OT. The rehab officer also left him with a cane and liquid level indicator. Mr M says he never had any arranged reviews and he gets in touch with the rehabilitation team when he has an issue. Mr W compares his current contact with the rehabilitation team with his initial contact when he was first diagnosed. He notes that the first contact with the rehab team was good because it was direct contact with Duchess Road. He says ***"it was when they moved to Birmingham that things started to go pear shaped. You now had to go through the call centre and leave your details. Then social services will do an assessment and half the council's call centre staff didn't know what they were talking about in terms of vision impairment. All the social services staff that worked for the vision rehab team did not have the specialist skills and the right skills to understand sight loss. It wasn't as plain sailing as it was when it was direct contact with Duchess Road. At Duchess Road, the staff had specialist skills, they had specialist equipment and a special set up. They had like a specialist kitchen, a couple of kitchens with marked cookers, microwaves, stoves with special dials. It was good because it meant that people that were not"***

comfortable in their own homes or had some problems or whatever could come in to a specialist setting and be trained in a specialist setting. Once they moved to Birmingham all this went”.

Mr M observes that Birmingham cut the number of its rehab workers, from 12 to about one full-time and one part-time post, which is having an impact on waiting times for rehabilitation support. He argues that *“this is ridiculous, cutting money from rehabilitation services, because for example Mr Smith comes to the hospital, he has been told he will go blind, obviously he needs support because he needs to eat, drink and he lives alone.’ Or he is going to injure himself with a knife. What’s going to happen without the rehab service? Mr Smith is going to go home, try to cook and burn his hands, burn the house down. It’s going to cost the NHS more to treat Mr Smith for the injuries that he is going to have. Where is the cost saving in that? I believe that prevention is better than cure”.*

Ms L is registered blind. After she received her CVI she had to chase the council to register with them. She called them and then had to wait for the vision rehabilitation officers to carry out an assessment. They started providing her with support but she couldn’t keep up with the training. Ms L was also suffering other health issues, such as problems with her back and kidneys, and she says it took her a long time to come to terms with her sight loss. As a result, she could not keep up with training such as mobility and says *“as soon as you can’t keep up then there is no more support”.* She compares the support she received from the council with other rehabilitation support she has received from charity organisations. Ms L finds the training received from the charity sector less regimented, more flexible and more relaxed. She explains *“I received all the rehab from the council, such as daily living skills (preparing food), mobility training, computer training. But the council computer training is nothing like the one provided by X charity (name redacted). This charity does it better, it’s more relaxed. The council seems to be more like ‘If you don’t meet it or keep up with the training by such and such a time then you’re going to have to stop it’. Whereas the charity one is more relaxed and went at my speed. Because when I started the computer training with the charity, they showed me what to do and I went to my house and tried it. When I explained my problems with the training the charity trainer brought it down to my level. I was able to learn at my own pace. The council did not give me the time to be able to really learn the skills I needed. Because of my health issues as well, it was hard and with the mobility training at the time, I found it difficult to walk. I was getting pressurised as well, telling me you have to do that and this, when I said I can’t do it then that was it. The person I also dealt with at the charity organisation was also blind so I felt he understood me and my needs. I still have other health issues and there are some weeks where I can’t make it (to charity X training) but they just tell me come back when you are ready. There is no pressure, which is a bonus”.* Ms L suggests that the vision rehabilitation team should be more understanding and patient. She says *“I know they have a job to do but be more compassionate, treat me the way you want to be treated. Just remember that people have different ways of coping and different timescales for coping, than the guideline. Not this thing of ‘You got to do this and this and this’ otherwise some back away. I backed away”.*

Mr S is registered blind and had some useful vision for some time. He lost all his sight ten years ago. He has been a guide dog user since the 1990s. However, since the end of May 2019 he has been without a guide dog and has just been recently informed that it will be a year until he gets a new one. He has never had any cane training so mobility is proving a challenge. He has had to rely on friends and family to go out, otherwise he is confined to the house. Since learning how long it will take to get another guide dog, he knows he is in need of cane training in order to be independent. He says that his confidence is not great at the moment. He says *“going out in the area where I live is risky because my long cane skills are poor. I have done it twice since last May, I was sort of rescued on the first occasion trying to cross the road. Since I lost the last of my sight, my confidence isn’t great. I am reluctant to go out, because going out using a cane and where I live is a busy place - it’s risky. I don’t want to take any risks”.* He does not know what the vision rehabilitation service offers and who to contact. He argues that people should not be reliant on the voluntary sector for support. He explains that he has been on the council’s register since the 1990s but never really needed their support because he always had a guide dog. However, he wonders why no-one has never contacted him to check if things have changed stating *“I have worked in Birmingham all my life and paid my council tax to Birmingham City Council, and paid national insurance. They should know that I still exist. So, when you talk about challenges, there is one”.*

Mr J was registered as partially sighted in 1974 and severely sight impaired in 2004. He received a call from the council and, following this discussion, the council put grip handles in the bathroom and at the front of the house. He also received cane training and other mobility training such as using traffic lights and crossing the road, going up and down the stairs. But he says for *“more than seven years now I have not had any contact with the council although my sight has worsened. I am now completely lost. They need to be asking people frequently how they are doing or how they are managing. There are so many facilities for blind people now. In the past they only showed you how to cross the street and so on. But now there is a lot more. Now all these new things have come*

that would improve my life and no-one has come to me. Since 2004 until now I have had no contact from BCC. No-one to check how am doing or if things have changed. I have heard that there are now gadgets which can help you feel secure. If you walk close to the wall or if someone comes close to you then it whistles or you can clap your hands to know where your keys are. I found out only two years ago that there are all these gadgets that can help me. There are also pocket alarms that are good for security, I have been robbed about three times so these new gadgets are useful". He suggests the vision rehabilitation team should revisit people who were diagnosed long ago.

Mrs R is not registered and has macular degeneration. She receives injections at the hospital but has not had any contact with the vision rehabilitation service. She says it was only two years ago that she had a phone interview following a fall, and three handrails were installed in her home. She was also given a white stick, magnifying glass and clocks. She points out that the person she spoke to over the phone did not mention registration with the council, but she was given contacts for a charity organisation which helped her complete forms for attendance allowance. Despite the lack of real contact with the rehabilitation team, Mrs R is grateful for the support she has received. She says ***"these things have provided me with the help I needed to maintain my independence and to keep me safe. It is hard to admit that your eyesight is worsening, I did not want all these bars/handrails but with the way my sight is, I couldn't do without them"***. She notes that as her eyesight has worsened she needs things like rails for the shower and mobility support. She has had to rely on her husband, who received some mobility training from a charity, to support her when she goes out.

Mr W is blind in one eye and has sight in the other. About four months ago the hospital stopped treatment because they said they cannot do anything more for his eyes. He had difficulty getting support from Birmingham City Council. He says ***"I had to go to the city council and spoke to the councillor. It is the councillor that helped me to speak to the council and social services called me and they came out to help me. Someone came out from the council and we discussed my needs. But they said they couldn't do much for me. They put some railings outside the house and some rails in the shower. I bought a white cane from a charity organisation and my wife helps me move about safely."***

Ms W is registered severely sight impaired/blind. She says that the time that she was contacted by the council often when you don't want to acknowledge your diagnosis but do need. She says ***"a social worker rang me and made a visit, I only met that social worker once. She arranged for me to go for white cane training which lasted six weeks. Everything lasts six weeks, you know, which is a bit rubbish considering my blindness doesn't last six weeks and you encounter different problems at different points in your life. When the council got in touch you are going through different emotions so for some things six weeks is not enough. However, to train me how to use my white cane, then yes, six weeks was enough. I had the most brilliant instructor but unfortunately their service was being cut and there were not many people working in rehabilitation as it was in the past so there was a waiting list for white cane training."***

Mrs B has trichiasis and macular degeneration. She has had 15 operations and has no sight in one eye but some residual vision in the other. Mrs B was told that she cannot be registered because she still has vision in one eye. She says that when she started struggling with getting in and out of the bath and having frequent falls, someone came to put a rail to help her with bathing. They also provided a seat and handrails for the toilet. Mrs B notes that she could not use the rail as she has no strength in her arm. As a result, her nephew has had to buy her a machine that lowers her into her bath. The toilet seat was unnecessary as she already had one.

Mrs B says that it would have been better to discuss her needs with someone when she began to lose her sight rather than when her sight has worsened. She says she can't go out to her garden because there are three steps which are unsafe without rails. The challenges she is facing, such as difficulties reading and frequent falls, have made her lose confidence. She says support from a charity has been a lifeline as ***"I went to this charity for four different days and they showed you how to do things such as making a cup of tea, and they also showed you how to measure how far the water is in the bath and got me a talking book and got me in touch with people to send me talking books. They have been very good."***

Appendix 3

What is Healthwatch?

Local Healthwatch were established in every local authority area across England following the Health and Social Care Act 2012. Our key role is to ensure those who commission, design and deliver health and social care services hear, and take into account, the public voice. Healthwatch Birmingham listens to and gathers public and patient experiences of using local health and social care services such as general practices, pharmacists, hospitals, dentists, opticians, care homes and community-based care. We hear these experiences via our Information and Signposting Line, our online Feedback Centre, and through our community engagement activity led by staff and volunteers. You can read more about the work of Healthwatch Birmingham here: <https://healthwatchbirmingham.co.uk/about-us/>

How do we select the issues we collect evidence about?

Some of the issues we hear about from patients and the public may require deeper exploration in order to present a comprehensive report to those who commission, design and deliver health and social care services in Birmingham. Members of the public select these issues as part of our Topic Identification and Prioritisation System. By involving members of the public in decisions about our future activities, we ensure we are operating in an open and transparent way. It also ensures that we understand the public's priorities.

Who contributes to our evidence collection?

We explore selected issues with the help of our volunteers, Healthwatch Birmingham board members, patients, members of the public, service users and carers. They share relevant experiences, knowledge, skills and support. Healthwatch Birmingham also talks to key professionals providing or commissioning the service we are investigating. This helps us to form a deeper understanding of the issue from the perspective of these professionals, and encourages them to take prompt action to implement positive changes for patients and the public.

What difference do our reports make?

We follow up our reports to see if our findings have made services better for patients and service users. We hold service providers and/or commissioners to account for changes they stated they would make in response to the report. If Healthwatch Birmingham finds no improvement, we may decide to escalate the issue to Healthwatch England and local regulators. We also monitor the changes to see if people experience sustained improvements

How to share your feedback about the issues heard in this study?

If you are a service user, patient or carer, please do share your experiences with us via our:

- Online Feedback Centre here: <https://healthwatchbirmingham.co.uk/your-feedback/>
- Information and Signposting line on 0800 652 5278 or by emailing us on info@healthwatchbirmingham.co.uk

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