

Out of Sight

The hidden scandal of vision
rehabilitation services across England

RNIB

See differently





- Children's
- Blood Tests & Pharmacy
- The Cobham Clinic
- Preoperative Assessment U
- Wards 20 - 26
- ↑ Accident & Emergency
- ↑ Zone J Gynaecology Health
- ↑ Zone K Fertility Centre
- ↑ ENT Clinic
- ↑ MRI Unit
- ↑ Outpatients Clinic
- ↑ Pathology
- ↑ X-Ray / Imaging & Scanning
- THANK YOU!

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Executive summary

Effective vision rehabilitation is life changing. Done well, it can help someone experiencing what could be sudden sight loss or a drastic change in circumstances with the vital support to retain their skills, confidence and sense of self.

Despite the legal right to this support under the 2014 Care Act, every year thousands of people with sight loss are not getting the support they need to thrive, holding people back from achieving personal goals and ambitions, or living the life they'd choose. Left unable to carry out everyday tasks safely, people are at risk of potentially fatal accidents, mental health crises and are giving up employment unnecessarily.

Vision rehabilitation is a forgotten, under-resourced system, lost among the many pressures facing local authorities. There is huge variation in the delivery of support across England, and without national oversight, there is no accountability of services provided. Services are under significant pressures due to increasing demands on adult social care, ever tighter budgets and a declining workforce of the specialists needed to provide the right level of support.

RNIB research shows that across England in 2022-23 blind and partially sighted people are missing out on services they are legally entitled to:

- A quarter (26 per cent) of local authorities had people left waiting more than a year for a vision rehabilitation assessment and subsequent support.
- 86 per cent of local authorities did not complete vision rehabilitation assessments within the ombudsman recommended 28 days, meaning nearly half (48 per cent) of blind and partially sighted people did not receive their assessment in this timeframe.
- Nearly a quarter (22 per cent) of local authorities have ongoing vacancies for specialist staff, and some areas have no vision rehabilitation specialists at all.
- A quarter (26 per cent) of local authorities are using non-specialists to undertake vital assessments.
- Local authorities acknowledge they are struggling to accommodate the rise in demand for rehabilitation services and have uncertainty around the future of its provision.

What's more, the gap between the health and social care system means many people are missing out altogether. Only just over half (56 per cent) of blind and partially sighted people we surveyed had received vision rehabilitation support in their lifetime. If this figure was representative of the entire adult registered blind and partially sighted population, at least 115,000 people would have been left without the support they're entitled to.

Effective support is not only profoundly important for individuals but it saves public money. In 2017, comprehensive cost-benefit analysis carried out by RNIB found that if just 25 per cent of expected positive outcomes were experienced by service users in Surrey, for every £1 spent on providing vision rehabilitation services, there was a cost reduction, avoidance or deferral of £9.33 within the local authorities budget; £8.63 within health and social care budget alone.

Ultimately, without tailored and comprehensive provision that takes account of the emotional turmoil people experience, blind and partially sighted people are being failed. It's critical the Secretary of State for Health and Social Care and local authorities take immediate action to reform and resource this service, so it supports everybody who needs it, when they need it.

Key recommendations

RNIB is calling on the Secretary of State for Health and Social Care to ensure all blind and partially sighted people can access the support they need to live life to the full. We need national oversight of services to ensure they are consistently delivered to the required standard.

To achieve this, we ask they:

- 1. Commission the National Institute for Health and Care Excellence to develop guidelines and quality standards, with local authorities having to report on these to government and publish annually.**
- 2. Subject vision rehabilitation services to the same regulation and monitoring as other adult social care services. This could be done within the current legislative framework and by extending the remit of the Care Quality Commission.**
- 3. Recognise the skill and expertise of Vision Rehabilitation Specialists (and Qualified Habilitation Specialists) by making Vision Rehabilitation Specialists a regulated profession.**
- 4. Encourage better integration of services through strengthened links between secondary and social care settings, with a guaranteed route in to vision rehabilitation for everyone who needs it, whilst ensuring blind and partially sighted people are made aware of their rights and the services they can expect to receive.**

What is vision rehabilitation?

It is estimated 1,880,000 people in England are living with sight loss, with a level of sight loss which is severe enough to have a significant impact on their daily lives.

Blind and partially sighted people can live confidently and independently. When a personalised package of care is received – and right support and equipment is put into place – people with sight loss can move around safely, adapt their workplace to stay in work, cook and continue to enjoy hobbies. This structured programme of support and guidance is called vision rehabilitation, an adult social care service funded through the local authority.

Effective vision rehabilitation is life-changing:

“The main thing that sparked a change in my confidence was seeing my rehabilitation specialist and getting to know him. Particularly for someone of my age at the time, being able to access a personalised service like rehabilitation can be the difference between struggling and thriving, because it doesn’t just help with navigation and cane training. It can change an entire mindset.”
(Severely sight impaired respondent)

Done well, vision rehabilitation should include a package of services like mobility or white cane training, emotional or peer support, technology training to use the accessibility features on a phone or software to read a computer screen. It should be personalised to help people continue to enjoy specific hobbies like gardening, sports or reading.

Support should be holistic and tailored to an individual’s circumstances whether they are of working age, retired or are a parent. Essentially, effective vision rehabilitation allows people with sight loss to continue living life to the full, maintain high expectations of themselves and achieve personal aspirations.

Vision rehabilitation is delivered by a Vision Rehabilitation Specialist. This is a highly-skilled role, undertaken by professionals who have studied to a minimum of a Level 5 qualification to support adults, who have acquired or have congenital vision impairment to live independently. The Rehabilitation Workers’ Professional Network (RWPN) is the professional body representing Vision Rehabilitation Specialists across the UK, who support the workforce in the day-to-day execution of their work by providing information, advice, guidance and learning opportunities.

The need for vision rehabilitation support doesn’t depend on the severity of sight loss or on a Certificate of Visual Impairment (CVI). Sight loss is a spectrum and every eye condition affects someone’s sight differently. Some people may be more affected than others by specific changes in

their vision, depending on what they use that vision to do. No two people's experience will be the same, so a tailored package of support is essential to ensure every person receives the support necessary to meet their personal needs.

Equally, vision rehabilitation services should be available at any point of someone's sight loss journey, whether sight loss is recent or it happened many years ago. Life changes – for example the loss of a partner – may create a new need for support even when someone's sight itself is stable. Everyone with sight loss is eligible to receive vision rehabilitation in England, and it's important this can be accessed easily.

After a referral into vision rehabilitation services, an individual should receive initial contact from the service – a phone call explaining what comes next within two working days. After a change in vision or sight loss, many people are at crisis point, and so it's essential they know what they can expect quickly. Services should then carry out an assessment to understand need in a "timely manner", defined by the Local Government and Social Care Ombudsman as 28 days, before going on to receive training and support.



What happens when effective vision rehabilitation is not in place?

Sight loss can be a major, life-changing diagnosis. For people adjusting to life with sight loss they must rebuild their confidence and cope with what can be a persistent level of anxiety, needing to weigh up the risk in every situation, as they complete daily tasks that they once found easier, especially at home and getting out and about. Yet RNIB research shows people are being left to manage alone. There is a huge lack of awareness of available support among blind and partially sighted people:

- Only just over half (56 per cent) of blind and partially sighted people surveyed have received vision rehabilitation support.
- For the significant amount (35 per cent) of blind and partially sighted people surveyed who had not received support, the main reasons cited were not being aware that support is available (58 per cent) and having friends and/or family who are happy to provide support (24 per cent).
- If this figure was representative of the entire adult registered blind and partially sighted population, at least 115,000 people would have been left without the support they're entitled to.

Without a clear pathway through secondary and social care, people experiencing sight loss can often be unaware of what to expect from vision rehabilitation services and the importance it has in supporting them to relearn essential life skills. Even those who are referred for support may be waiting without specialist support for lengthy periods, essentially having to learn to 'get by' themselves.

In practice, this means people often rely on their pre-existing (potentially, very limited) knowledge about how blind and partially sighted people live their lives to envisage their future. Sadly, we know this tends to people reducing aspirations for themselves, dropping out of the workforce and curtailing their lives. Time and time again we hear about mental health crises following sight loss, from people who now believe their life as they knew it is 'over'.

"With the waiting time [for support], after diagnosis. [I felt] so vulnerable and trapped, it was horrible." (Severely sight impaired respondent)

RNIB has been told about occasions when lengthy waiting times have led to accidents and injury, and in one case a tragic fatality – while the person waited for local authority intervention.

Accidents and near-misses are common, damaging confidence:

"I nearly got run over. This would be about six months [after receiving a diagnosis]. I'm in tears. I phoned up the social services and said: "You know, I really do need whatever it is that support is supposed to happen at this point." A couple of weeks later, the Vision Rehabilitation Specialist came out." (Severely sight impaired respondent)

Aside from the obvious benefits to the individual, an inadequate service will cost local authorities more in the long run. Early intervention reduces the need for referrals into other more costly services, improving health and saving lives.

In 2017, comprehensive cost-benefit analysis conducted by the Office for Public Management, when commissioned by RNIB, found if just 25 per cent of expected positive outcomes were experienced by service users in Surrey, for every £1 spent on providing vision rehabilitation services, there was a cost reduction, avoidance, or deferral of £9.33 across the local authority. This figure would be £8.63 if the focus was on the health and social care budget.



Natalie's Story:

A six month wait for life-changing support

Natalie Holford, age 60, has Marfan's syndrome and was registered severely sight impaired in April 2019 following a stroke.

She did not get any vision rehabilitation support until September 2019, when she then received support from her local Vision Rehabilitation Specialist.

"I have been living with sight loss all my life, but my parents decided that I should be brought up "normal". So, there were not any allowances made and I never had any formal rehabilitation. I was certified as severely sight impaired in April 2019 after having a stroke.

"It was an emotional blow to have this piece of paper. I had started to feel unsafe going out and thought other



people might think I was stuck up or stupid because I was not interacting with people.

"When it was suggested that I needed help, I still fought against the stigma. But one day, I went out and nearly got run over, and I realised that I needed help.

"Often speaking to social services can be a really big step to take for people and I had always shied away from it.

"I eventually did phone social services and waited six months for contact. I felt very unsafe and imprisoned and I could not even go out or get on a bus. It was at a time when I had just moved to a new area which I did not know very well. I was not well at that time. I had to cross a busy road and a car came round the bend and started hooting at me. I was about three quarters of the way across the road and I suddenly felt very, very trapped.

"After that I was scared that I might get run over and frightened that I might become a hermit. Previously I had been a life coach and I knew the sort of things I needed to be doing but I had all these barriers to my independence.

"It took me about six months and two phone calls to receive some support from a rehabilitation specialist. My support finally arrived in September 2019, and it was a lovely lady who couldn't do enough for me.

“Support from my Vision Rehabilitation Specialist focused on how to make [my] home the very best.

“She helped me with bump-ons [tactile markers that people feel to know where a dial is pointing to or where a mark on a jug is] and various things around the house. [She] also gave me a pair of talking kitchen scales and they have been brilliant. I took up bread baking during the pandemic and it was great weighing out ingredients.

“And then we did white cane training. Initially, I was so adamant that I didn’t want to use a white cane... but she encouraged me to give it a go.

“It gave me balance, and the confidence I needed. I had worried initially about looking vulnerable because of the white cane, but actually I’ve always felt rather more empowered that people will come and ask if I need any help. Now, I don’t go out of the house without the cane.

“I began to be able to feel my way up and down the streets and we went walking in the park and she showed me how to measure distances so I could find my way home.

“Now I’ve got the white cane, people will come and ask me if I want to cross, and as long as they walk with me across the road, that helps.

“My vision rehabilitation support was very good, but I have heard that it’s a postcode lottery across the West Midlands.

“There were other places that were having telephone conversations, and



Bump-ons are tactile markers that people feel to know where a dial is pointing to or where a mark on a jug is. In this image the orange raised stickers are being used to indicate the time settings on a microwave oven.

sending out equipment, advising people to use YouTube to learn how to do things. But I know that there is nothing that replaces a Vision Rehabilitation Specialist watching you use your cane.

“If I hadn’t known what was available, I wouldn’t have kept pressing for support. I had actually done a Living Well with Sight Loss course with RNIB which helped me to know what support I should have been getting from my local authority. I wish I could have known so much earlier about the things I could have had access to.”

Natalie now volunteers for RNIB as a facilitator on the Living Well With Sight Loss course.

What the Care Act says

The Care Act 2014 [3] – and associated guidance [4] – places a legal duty on English local authorities to prevent, reduce and delay the need for care and support.

Vision rehabilitation is provided as part of local authority tertiary prevention / formal intervention services; these aim to minimise the impact of an impairment and support people to regain skills and manage or reduce need where possible (para 2.9, Care and Support Statutory Guidance) [4].

Some local authorities provide an in-house service; others outsource these services to local sight loss organisations or other external provider. When outsourced, local authorities remain responsible for these services and should correctly record and store all associated data.



The Care Act also dictates that aids (up to a value of £1,000 per item) and minor adaptations (up to a total cost of £1,000) – as recommended by the specialist assessor – must be provided at no cost to the person being supported, so they are available for use during rehabilitation training (paras 2.60, 2.62 and 8.14, Care and Support Statutory Guidance.)

Aids should not be restricted to a pre-approved list but should reflect the best way of meeting an individual's needs and maximising independence.

There is an expectation that the assessment process should start from the moment the local authority begins to collect information about an individual [6.2]. The assessment may be the only contact the local authority has with the individual at that point in time, so it is critical that the most is made of this opportunity [6.4].

The assessment aim is to identify needs and outcomes to help people improve their wellbeing [6.5]. Guidance sets out that an assessment is important to identify any prevention needs [6.60].

The person under assessment should be able to participate in the process as effectively as possible. In statutory regulations it states assessments must be carried out by a person that has the necessary skill, knowledge and competency.

Our research

RNIB issued a Freedom of Information (FOI) request to all upper tier local authorities in England, asking a range of questions about the current vision rehabilitation service offered in the local area. 143 of the 153 local authorities in England responded, or had a response submitted by an external provider whom they commissioned to deliver the service, giving a response rate of 93 per cent.

Vision rehabilitation is a devolved policy area. This FOI research covers England only.

Our FOI requests to the local authorities covered:

- The amount of people receiving vision rehabilitation
- The age breakdown of those receiving vision rehabilitation
- The average waiting times for vision rehabilitation assessments and support
- Detailed information regarding the support on offer
- Certificate of Vision Impairment management
- How vision rehabilitation is provided – and who provides it – across the local authority
- Workforce capacity.



Also, RNIB spoke with 437 blind and partially sighted people from across the UK through a series of focus groups and a survey in order to better understand their experiences and perspectives of the vision rehabilitation support which they received.

Additionally, as part of our strategic planning process we surveyed RNIB employees with sight loss. We asked them to tell us about their vision rehabilitation journey and what helped them adapt to their sight loss.

Vision rehabilitation now

How vision rehabilitation assessments are conducted

Before tailored support can begin, every blind and partially sighted person must receive a specialist assessment to identify how they may benefit from rehabilitation support. We believe these appointments should be face-to-face as telephone assessments are likely fail to recognise or identify every aspect of sight loss which an individual is experiencing.

When asked how these vision rehabilitation assessments are conducted: 89 local authorities stated all assessments are conducted face-to-face; 49 said a combination of both face-to-face and telephone assessments are used; and two local authorities confirmed they only use telephone assessments to assess an individual's needs.

Three local authorities said they didn't know how specialist vision rehabilitation assessments are delivered. 27 of the 49 local authorities who provide a combination of face-to-face and telephone assessments could not provide additional information to the split of these assessments.

Waiting times for support

Across England, services provided by local authorities vary: from good to poor. Our FOI requests found that local authorities are experiencing a rise in demand for vision rehabilitation

services, with many acknowledging it is becoming more challenging to meet this demand.

Some parts of the country also experience periods where they operate with no service at all, with no fully trained Vision Rehabilitation Specialist in post. This has led to overstretched services and lengthy waits, with some focus group respondents citing waits of up to two years.

As outlined above, long waiting times in effect lead people in need of support to 'get by' alone. We hear from people who are not 'waiting well' for vision rehabilitation, meaning their care needs are far greater by the time they receive a specialist vision rehabilitation assessment.

Our focus group participants told us:

"It's a bit tiring waiting because it's just promises and promises. 'We'll do this. We'll do that' and then there's no answers... so you have to hit rock bottom. I've been asking for help for so long and now I just want to see what's going to happen. I just want them to put themselves in our shoes and to say 'if that was you – or – if it was somebody from your family, what would you be doing?'"

We also hear from people who – after a positive experience in one area – feel additional support to navigate a new location is needed when they move. As this becomes a fresh referral (to the "new" local authority) they must essentially go through the same waiting process again. Lack of communications

between the authorities can often create further delays.

Initial contact

Initial contact from the local authority is an essential first step on everyone's rehabilitation journey. It should help people understand what to expect: the benefits of vision rehabilitation, the registration process and more about the process of getting a specialist assessment.

Initial contact can also ensure that people understand that they can request support from their local authority at any time, even if they don't need additional support immediately. When timely communication is not received, people are left without adequate support or knowledge of the process, feeling adrift, and unaware of the support they can expect.

RNIB believes blind and partially sighted people should receive initial contact by telephone within two working days of the local authority's receipt of a CVI, referral or self-referral for support, to ensure that specialist assessments go on to be completed within 28 days.

However, when the FOI request asked local authorities to provide how long people had to wait for initial contact from the local authority, following the local authorities' receipt of a CVI or request for an assessment, within the 2022/23 financial year, in most cases the wait was longer.

Of the 111 local authorities who provided this data, 77 (69 per cent) reported a response time of more than three working days.





Local authorities vary in how they make such initial contact. This can come in the form of a telephone call from a generalist team, telephone call from a specialist within the sensory team, via email and by post.

We were pleased to see so many local authorities contacting people using a telephone call from the specialist sensory teams (89 local authorities). We believe it is not acceptable to only send a letter through the post, which six local authorities told us they do. This could lead to people slipping through the net, as they may be unable to read or access its content or have to rely on sighted assistance to be able to follow the steps outlined within the letter.

Specialist vision rehabilitation assessments

The FOI request asked local authorities how many people experienced given waiting times between referral and receiving a specialist vision rehabilitation assessment in the 2022/23 financial year.

Of the 143 local authorities which responded to the FOI:

- 80 provided this numerical breakdown while 22 provided an average waiting time across their local authority.
- 41 local authorities informed us this data was either unknown, or recorded in a way which is not reportable in the format we requested.

Of the 80 local authorities who provided a numerical breakdown:

- 86 per cent of local authorities did not complete vision rehabilitation assessments within the ombudsman recommended 28 days.
- There were 21 local authorities (26 per cent) which had people waiting over a year for a vision rehabilitation assessment.
- This means nearly half (48 per cent) of blind and partially sighted people are not receiving their assessment within the ombudsman-recommended timeframe of 28 days.

RNIB has heard directly from many blind and partially sighted people who have experienced wait times far beyond what is safe or expected, but to find at least 2,025 people were left waiting for more than six months to receive a vision rehabilitation assessment is shocking.

Waiting for support to begin

While many people wait far too long to receive a vision rehabilitation assessment, it seems from our research, in most cases, specialist support begins relatively promptly after the assessment.

63 local authorities confirmed support begins directly following a vision rehabilitation assessment, or within 28 days of the assessment taking place. An additional eight said support began within two months of the assessment. However, 44 local authorities do not store this information, or store it in a way which is not recordable for the FOI request.

Local authorities provided several reasons to explain why the waiting times for assessments are so long.

These included:

- Workforce shortages and recruiting challenges.
- Significant rise in demand.
- A backlog in cases following the COVID-19 pandemic.
- Insufficient links between secondary and social care. This can result in local authorities not receiving CVIs in a timely manner from hospitals.

One local authority told us:

"A CVI was received last week (17 October 2023) which was completed by a Consultant Ophthalmologist at a private hospital in July 2023."

Why carry out vision rehabilitation assessments within 28 days?

A clear timeframe for assessment enables a person to know what they can expect, so people are not left on their own for long periods of time to struggle, increasing the risk of negative outcomes. Although in legislation and guidance, an assessment must be carried out in a "timely" way, RNIB defines this as up to 28 days.

The Local Government and Social Care Ombudsman (LGSCO) identified the figure of 28 days for an assessment to be completed in a report into a complaint in Hammersmith and Fulham [5], taking this from the agreed policy on visual rehabilitation of the Association of Directors of Adult Social Services (ADASS) [6]. In a previous decision, the LGSCO considered that local authorities should ordinarily complete a social care needs assessment within four to six weeks [7].



Mobility and other elements of vision rehabilitation support

Our research shows that the most common type of support blind and partially sighted people receive is long cane training and how to use low vision aids. All 143 of the local authorities responding to the FOI confirmed they provide daily living skills (such as cooking, dressing and cleaning) and orientation / mobility training as part of the vision rehabilitation offer.

"I consider vision rehabilitation and learning these adjustments to be the main factors that helped me gain my first job. I went from doubting that I could do a lot of things, to saying why not?"
(Severely sight impaired respondent)

Participants in the focus group shared that once they received long cane training, they were happy with it. One focus group participant spoke about how "magical" they found the white cane to be, after it has given them a sense of independence.

"I think that the Vision Rehabilitation Specialist was the person who made most difference to me. Teaching me how to use the white cane revolutionised my life, the white cane has been like my magic wand really giving me confidence and allowing others other people to know what to do with me, really because it's a sign that there's something up with my eyes."
(Severely sight impaired respondent)

"Vision rehabilitation [has] made significant difference to me having the [white] cane actually because I'd completely lost my confidence going out."
(Sight impaired respondent)

However, there are types of support which the FOI found are not routinely funded through adult social care which would be beneficial for blind and partially sighted people. These include:

- Technology support
- Advice about benefits and finances
- Emotional / psychological support
- Support or advice for family / carers
- Provision of 'high tech' equipment such as tablets

Instead, local authorities are signposting to other organisations who offer these types of support.

RNIB believes the vision rehabilitation offer must reflect the increased use of technology across society and be an opportunity for blind and partially sighted people to gain and develop digital skills. It must ensure every individual gets access to all the skills and support they need to take advantage of mainstream and assistive technology which can be invaluable in the modern world.



A threat to Vision Rehabilitation Specialists

In line with the Care Act, specialist assessment must be completed by someone with the appropriate skills, knowledge, training and qualifications to understand the nature of the support which may be needed.

We believe this work cannot be effectively undertaken by outreach workers or occupational therapists, as they lack the understanding and required training of the many different eye conditions, and the impact they have on everyday life. While intermediate support from a non-specialist may be appropriate in some cases, assessments and specific support must be delivered by a specialist:

"I had an occupational therapist before that because of the stroke and she didn't really know what to do with me. She did try to send me out on a walk, but she realised I needed specialist assistance from a low vision perspective. So that was challenging." (Severely sight impaired participant)

However, there are several ongoing issues currently experienced across local authorities which means those delivering vision rehabilitation support aren't always those who will hold the requisite experience and knowledge. There is no consistency in the size, or makeup, of sensory teams within local authorities. The number of employed Vision Rehabilitation Specialists varies from one part time specialist to a

team of 9.5 FTE (full time equivalent). However, demand, of course, for support does differ greatly too. The number of non-specialists who contribute to the vision rehabilitation has also increased.

These posts include:

- Occupational therapists
- Wellbeing officers
- Social workers
- Vision Rehabilitation assistants
- Community Assessment officers

Local authorities told us they are struggling to recruit Vision Rehabilitation Specialists.

This has been an ongoing issue for many years exacerbated by workforce attrition. It takes time to become a specialist in vision rehabilitation, and we know of individuals who have left the profession for higher earning roles once they have qualified.

To become a Vision Rehabilitation Specialist you must have qualified with a defined and specific qualification. Only those who undertake the mandatory two-year training can become registered professionals, but training facilities are limited.

When vacancies arise within local authorities it is not always a guarantee there will be either the interest or capacity to fill these roles, which can often mean the posts remain vacant for many months.

One local authority told us:

“There is a national shortage of skilled staff for sensory roles within local authorities, making the recruitment of staff challenging, although our retention of staff is good and positive.”

The FOI found almost a quarter (22 per cent) of responding local authorities (31 local authorities – one of which had two posts vacant) have lost specialist staff in recent years, meaning there are currently 32 vacancies: 27 FTE and five part time roles.

Shockingly, two local authorities currently do not have any Vision Rehabilitation Specialists. Yet the Regulations and Guidance from the Care Act requires that those carrying out assessments have the skills and knowledge to carry out the assessment of specific conditions that they are being asked to assess.

Unless local authorities can fill the current vacancies in some way, it is not clear to RNIB that these local authorities will be in a position to meet their legal obligations in relation to assessment.

As a result of these vacancies, 37 of the 143 local authorities which responded to the FOI told us that vision rehabilitation assessments are not always conducted by specialists – a total of 26 per cent of local authorities using non-specialists to undertake vital assessments.

Several local authorities shared that they are having to respond to the challenges they are facing due to the increased demand by looking to recommission sensory services in the future. Some local authorities are responding innovatively, now commissioning a ‘grow your own’ model to increase the number of rehabilitation specialists within their teams. Here, local authorities are not filling permanent vacancies and instead having an apprentice to fill this position, who would, once qualified, formally take on the permanent role. However, this still means a wait for a fully qualified role.

The challenges caused by the workforce shortage were also commented on in terms of the long-term stability of the services local authorities can offer.

One local authority told us:

“The future provision of vision rehabilitation services may be at threat due to the limited opportunities to train as a specialist, the limited opportunities to go into the apprenticeship route and the limited funding available to local authorities to support succession planning.”

The solutions

Quality standards

Although the Care Act makes the provision of vision rehabilitation a statutory duty, as part of wider rehabilitation services, rules around quality standards and legislation around regulation and data collection have not kept pace. There is no universal set standard of what is provided by local authorities.

This is reflected in blind and partially sighted people's experiences of rehabilitation, which, as outlined above, often concentrates on mobility and practical household skills, without offering the technology support or in-depth emotional support it could.

In other areas of health and social care, clear quality standards are used to define what good provision looks like. These are defined by the National Institute of Clinical Excellence (NICE) and are then used by commissioners to support in commissioning services or quality improvement work, help ongoing quality assurance, and to shape services. They can also be used by patients or service users to understand what should be available to them.

Each quality standard includes a set of statements to help improve quality and information on how to measure progress. In effect this provides a framework for setting standards and measuring adherence to them.

Example Quality Standards in similar topic areas include:

- Intermediate care including reablement
- Rehabilitation after critical illness in adults
- Social care for older people with multiple long-term conditions.

Blind and partially sighted people often prefer to learn about the support available to them from other blind and partially sighted people. However, inconsistencies in the range of services offered across England mean the support an individual can expect varies so wildly from one authority to another that the experiences of someone elsewhere in the country can bear little resemblance to that on offer locally. As a result of the differences between local areas, if you move between local authorities, your experience of vision rehabilitation is also likely to differ.

There is an urgent need for clarity about what skills and support should be provided through vision rehabilitation, to ensure blind and partially sighted people are equipped with a comprehensive set of skills for independent living.

We are therefore calling on the Secretary of State for Health and Social Care to commission the National Institute for Health and Care Excellence to develop guidelines and quality standards for vision rehabilitation.

RNIB is developing a proposed Outcomes Framework for post diagnostic support and we stand ready to support in the creation of

these quality standards. There is also a wealth of professional expertise available to feed in from bodies like the RWPB and the Clinical Council for Eye Health Commissioning.

Clear, defined standards would enable both local and national oversight of performance. Vision rehabilitation (and preventative services in general) are further in the unique position in adult social care services as they are the only specialist-assessed service not monitored or inspected by care regulators such as the CQC.

Not needing to report outcomes has, we believe, resulted in a consequent lack of accountability and priority for the service within local authorities. And without local, or national, performance monitoring of the services provided, it is difficult for anyone to fully understand what the state of provision is like across local authorities.

Inconsistent data handling by local authorities has meant that throughout our FOI request process, there has been little consistency in how local authorities have responded to the questions we posed, with many local authorities even saying they were unable to provide details due to lack of data about the overall services provided.

These responses have reinforced our view that proper oversight of services is urgently needed, to ensure they are delivered to the right standards which meet service need.

Blind and partially sighted people do not feel the current provision

of vision rehabilitation goes far enough to address the many aspects and potential challenges which arise from losing your sight. Half of survey respondents felt the vision rehabilitation support they received did not sufficiently address any emotional and psychological impact of their sight loss. More concerningly, only 20 per cent stated they felt less lonely, or isolated, as a result of this support.

One survey participant told us – what they believed – a good rehabilitation service should deliver:

“I’m embarrassed to say that certainly with learning to use a cane, I resisted it at first, thinking it was a big blind badge, but one day the penny finally dropped that the cane was my magic wand and the secret to getting out there without injuring myself or others. So much of my journey has been accepting my sight loss and then going on to do the things I wish to do.

The fear of failure or fear of the unknown can be so powerful and can hold someone back for a lifetime, if they let it. I feel so strongly in that we should be teaching and inspiring newly blind people to accept their sight loss the healthy way and that will open the door to them living a much happier fulfilled life.” (Survey participant)

We are asking the Secretary of State for Health and Social Care, after commissioning quality standards, to: **Subject vision rehabilitation services to the same regulation and monitoring** as other adult social care services. This could be done within the current legislative framework and by extending the remit of the Care Quality Commission.

Workforce regulation needed

Although an extremely specialist role, with two years' extensive training required, vision rehabilitation is currently not a regulated profession.

This means unlike those in comparable regulated professions – like Occupational Therapists – Vision Rehabilitation Specialists do not currently have to undertake a compulsory programme of Continuing Professional Development (CPD). CPD is a vital component in maintaining standards and securing consistent service delivery around the country, whilst also offering reassurance to those being supported.

During our research, one survey participant told us:

"I had to train my Vision Rehabilitation Specialist how to use a screen reader because he'd never encountered one before."

Screen readers are the tool many blind people use to "read out" a website rather than viewing it. It is concerning that a specialist was not aware of this or in a position to demonstrate the advantages of using the equipment

to those they were supporting. Had this specialist been subject to ongoing training through CPD and been monitored on service delivery, it is almost certain he would have been made aware of the use of screen reader technology which is invaluable to many blind and partially sighted people.

Clearly, more needs to be done to ensure there is adequate resourcing within sensory teams, which retains, and constantly develops, the specialist skill of Vision Rehabilitation Specialists, whilst further ensuring those who need support get it.

Recognising the role and value of qualified Vision Rehabilitation Specialists would ensure all those delivering support are working to a high standard, are accountable for their work and have ongoing access to training to develop their skills. This would further aid the introduction of quality standards, whereby the same standard of care could become to be expected across the country. Giving these professionals the same prestige as others in health and social care would open this specialism up to more people, helping the ongoing workforce crisis.

In 2017, RWPN launched a formal structure for CPD that is a requirement of its membership, although membership to the network is voluntary. The lack of statutory professional registration status across all four countries of the UK, remains a priority area of campaigning activity for RWPN. In 2022, RWPN was awarded Accredited Voluntary Register status by the Professional Standards Authority, which is a step in the right direction.



However, given the extensive nature of training and specialist nature of the work, it is important this role is brought into line with other health and social care specialists.

We are asking the Secretary of State for Health and Social Care to:

Recognise the skill and expertise of Vision Rehabilitation Specialists (and Qualified Habilitation Specialists) by making Vision Rehabilitation Specialists a regulated profession.

Access to vision rehabilitation

There is variation in how somebody can refer into vision rehabilitation, whether it be following referral from the hospital with a CVI or self-referral. Regardless of an entry route, RNIB believes it must be clear, easy and

simple for people to have contact with the local authority.

There can be significant time differences in how long it can take local authorities to receive a signed CVI from a health professional once issued. These insufficient links between secondary and social care are further prolonging the waiting time for support, at detriment to blind or partially sighted people. More joined up work is needed to ensure consistency of services across the country.

Findings from our recent surveys and focus groups have shown that if a person is prepared to push to gain the help and support – to advocate for themselves – they are likely to receive good quality support. However, we don't believe this is nearly good enough.

“You have to be assertive. You have to be an advocate for yourself and you have to push things otherwise you [are] just not going to get anything. But the service I have had has been and [the] Vision Rehabilitation Specialist [was] absolutely brilliant. We... have to have the soft skills to communicate and sort of fight our own cause and if we don’t have those, we just get left and that is just terrible really.”
(Severely sight impaired participant)

Some focus group participants reported a lack of confidence in gaining support and stated that they found the system of seeking support to be frustrating.

“I think a big part of it was lack of confidence and frustration with the whole system [which] was frustrating. It wasn’t just accessing services, but that sort of limbo. I just felt in limbo I couldn’t move on with my life properly.”
(Sight impaired respondent)

Some participants shared their concern for those who are not able to push for support:

“I’m somewhat concerned that people that aren’t as confident don’t really get a service and they really should be getting a service.” (Severely sight impaired respondent)

This reinforces our view that greater efforts must be made to ensure all blind and partially sighted people are made aware of their rights and the services they are entitled to expect. People should not be made to have to fight for legal entitlements but offered them in a timely manner.

We need Integrated Care Boards to:

Encourage better integration of services through strengthened links between secondary and social care settings, with a guaranteed route in to vision rehabilitation for everyone who needs it, whilst ensuring blind and partially sighted people are made aware of their rights and the services they can expect to receive.

Our conclusions

Vision rehabilitation is not granted the same level of significance as other adult social care services, despite being a lifeline for many blind and partially sighted people. As our research shows, this has resulted in services being effectively 'out of sight', not prioritised by decision-makers and commissioners, leading to widespread ignorance about its benefits.

When people like Natalie (see page 10) get support, they gain the confidence to live life to the full. However, our research has shown how – when a structured programme of vision rehabilitation support is not implemented in time – blind and partially sighted people face an increased risk of harm. This is happening too often and putting lives at risk.

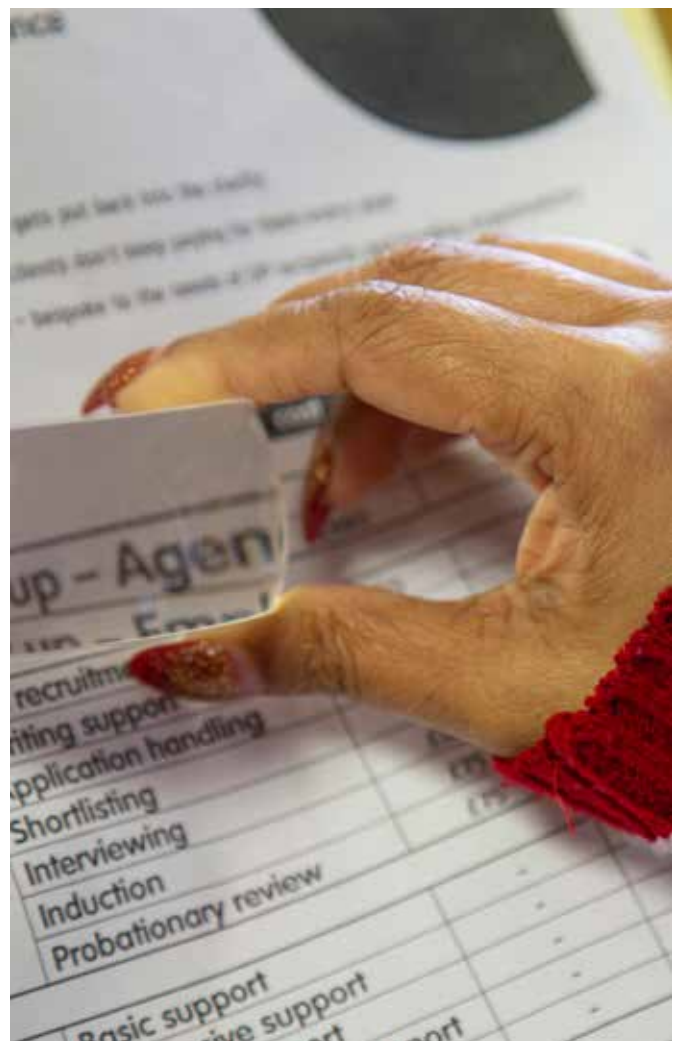
It is evident that access to support and care post-diagnosis via adult social care is effectively a postcode lottery. This has got worse due to growing demands on already-stretched resources locally. However, demand for vision rehabilitation will only grow, as more people in England live with sight loss. By 2050 the number of people with sight loss in the UK will double to more than four million [1,2].

The biggest challenge is addressing the lack of resources to meet the growing demand for vision rehabilitation services. RNIB is concerned that future provision is at risk, given the ever-increasing

demands on adult social care finances and the decline in the trained workforce needed to deliver this care.

As this report has laid out, it is imperative local authorities respond to the growing waiting lists for support, by providing timely and consistent access to vision rehabilitation for everyone with sight loss.

Vision rehabilitation services must be included as part of any drive to improve performance of the overall health and adult social care system; and the Secretary of State for Health and Social Care must encourage better integration of services through strengthened links between secondary and social care settings.





Recommendations

RNIB is calling on the Secretary of State for Health and Social Care to urgently review vision rehabilitation services and to ensure all blind and partially sighted people can access the support they need to live life to the full. We need national oversight of services to ensure they are consistently delivered to the required standard.

To achieve this, we ask they:

- 1. Commission the National Institute for Health and Care Excellence to develop guidelines and quality standards**, with local authorities having to report on these to government and publish annually.
- 2. Subject vision rehabilitation services to the same regulation and monitoring** as other adult social care services. This could be done within the current legislative framework and by extending the remit of the Care Quality Commission.
- 3. Recognise the skill and expertise of Vision Rehabilitation Specialists** (and Qualified Habilitation Specialists) by making Vision Rehabilitation Specialists a regulated profession.
- 4. Encourage better integration of services** through strengthened links between secondary and social care settings, with a guaranteed route in to vision rehabilitation for everyone who needs it, whilst ensuring blind and partially sighted people are made aware of their rights and the services they can expect to receive.

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Appendix

10 blind and partially sighted people (eight women and two men) took part in three online focus group sessions (attending two sessions lasting two hours, 15 minutes each).

In the survey, 427 valid survey responses were recorded. Key demographics for the unweighted sample are listed below.

- 58 per cent of the people we spoke to were registered blind / severely sight impaired, 33 per cent were registered partially sighted / sight impaired, and nine per cent had a vision impairment but were not registered.
- The majority of the sample at 45 per cent had lived with sight loss for 20 years or more and 41 per cent from 4 to 19 years. 10 per cent were more recently diagnosed, living with vision impairment for one to three years.
- 30 per cent of the sample had their sight loss diagnosed in childhood, 45 per cent during working age, and 22 per cent diagnosed after they were aged 65.
- 62 per cent were aged 65 and over, 38 per cent were aged 16 to 64.

Table 1

Table shows how long people had to wait for initial contact from the local authority, following the local authority's receipt of a CVI or request for an assessment, within the 2022/23 financial year.

(Table has 2 columns and 10 rows)

	No. of local authorities
A) 1 to 3 days	34
B) 4 to 10 days	43
C) 11 to 20 days	15
D) 21 to 31 days	9
E) 1 to 3 months	6
F) 4 to 6 months	3
G) Over 7 months	1
Mix of waiting times	12
Information Unknown or not recorded in a reportable way	20

Table 2

Table shows how local authorities made this initial contact:

(Table has 2 columns and 7 rows)

	No. of local authorities
A) A telephone call from generalist team	12
B) A telephone call from our sensory team	89
C) By post	6
D) Other	30
Both B and C	5
Information Unknown	1

Table 3

Table shows the total amount of people who experienced different categories of waiting times between referral and receiving a specialist vision rehabilitation assessment (2022/23 financial year) according to the 80 local authorities who provided this information.

(Table has 2 columns and 8 rows)

	No. of people
Less than 28 days	9,193
1-2 months	3,293
3-4 months	2,025
5-6 months	1,171
7 months – 1 year	1,465
Over 1 year	560
No. of local authorities who do not collect this data in a recordable way	41

Table 4

Table shows the average waiting time of people waiting for vision rehabilitation assessments out of the 22 local authorities who provided this:

(Table has 2 columns and 7 rows)

	No. of local authorities
Less than 28 days	8
1-2 months	4
3-4 months	4
5-6 months	2
7 months – 1 year	4
Over 1 year	0



Contact us

RNIB is keen to talk with policy makers and local authorities about how to ensure every blind and partially sighted person gets access to the vital skills and support they need to thrive.

Please contact us:



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