# Voice of the Customer: Blind and Partially Sighted People’s Experiences of Vision Rehabilitation

**Autumn 2023**

Insights into the lives of blind and partially sighted people in the UK and the issues that matter most to them. This time on their experiences of accessing post-diagnosis vision rehabilitation support.

## Contents

[1. Executive Summary 2](#_Toc160015114)

[1.1 Key findings 2](#_Toc160015115)

[2. Background 2](#_Toc160015116)

[2.1 Who we spoke to 2](#_Toc160015117)

[3. Findings 3](#_Toc160015118)

[3.1 Awareness and signposting 3](#_Toc160015119)

[3.2 Harmful consequences of long waiting times 5](#_Toc160015120)

[3.3 Support is heavily focused on mobility 6](#_Toc160015121)

[3.4 Hidden support – the role of family and friends 11](#_Toc160015122)

[3.5 Those who can self-advocate find better support 12](#_Toc160015123)

[3.6 Need for continuous support 13](#_Toc160015124)

[3.7 Need for a ‘sight loss-informed’ provider 14](#_Toc160015125)

[4. Recommendations 15](#_Toc160015126)

[4. Appendix 16](#_Toc160015127)

[About RNIB’s research 17](#_Toc160015128)

## Executive Summary

Every year 100,000 people will receive a significant and life changing diagnosis and advice and support is not currently automatically embedded within clinical pathways.

Our research highlights that blind and partially sighted people are not getting the right support and information they require on their journey. With demand for eye care at an all-time high, there is need to alter the pathway as people with sight loss are currently being failed by the system.

### Key findings

* **Increased risk of harm due to lengthy wait times.** Blind and partially sighted people are having to wait between 1 month to 1 year after diagnosis to receive support. This has led to some experiencing harm and encountering dangerous situations such as burning when cooking and near-accidents when travelling outside.
* **Lack of signposting and clarity of provision.** Blind and partially sighted people are receiving limited or unclear information about what support is available and where.
* **Reliance on self-advocating.** Blind and partially sighted people tell us that they feel they need to be proactive and make the effort to find suitable support.
* **Mobility-focused.** Our findings indicate that vision rehabilitation training is heavily focused on mobility training, with the potential detriment to other key practical forms of rehabilitation such as independent daily living tasks (cooking, cleaning), personal care (eating, dressing, bathing) and being able to travel independently.
* **Hidden support.** Our findings indicate that blind and partially sighted people are having to rely on family for key aspects of support. This implies that family play a key role in filling the gaps in support provision.

## Background

We carried out a series of focus groups and a survey to better understand blind and partially sighted people’s experiences and perspectives of vision rehabilitation support.

### Who we spoke to

10 blind and partially sighted people (eight women and two men) took part in 3 online focus group sessions (attending two 2 hour 15 minutes sessions).

The survey was open to anyone with a vision impairment over the age of 16. A large portion of the fieldwork was collected via outbound calls with support from our Telephone Fundraising Team.

In total, 427 valid survey responses were recorded. Key demographics for the unweighted sample are listed below. Throughout the rest of the report, the responses have been weighted to be more representative of the population with a vision impairment.

* 58% of the people we spoke to were registered blind/severely sight impaired, 33% were registered partially sighted/sight impaired, and 9% had a vision impairment but were not registered.
* The majority of the sample at 45% had lived with vision impairment for 20 years or more and 41% from 4 to 19 years. 10% were more recently diagnosed, living with vision impairment for 1 to 3 years.
* 30% of the sample had their sight loss diagnosed in childhood, 45% during working age, and 22% diagnosed after they were aged 65.
* 62% were aged 65 and over, 38% were aged 16 to 64.

## Findings

### Awareness and signposting

While nearly half of our sample (49 per cent) felt aware of what vision rehabilitation support is available where they live, the majority of participants (38 per cent) felt less aware of what entitlements are available to help towards equipment or adaptations for blind and partially sighted people where they live.

Survey participants often stated that they received information about what they were entitled to from charities such as RNIB:

“RNIB contacted me, and I learned about what was available from the person that rang me. I have had no contact from local authority. I got post stroke help from the health authority but specifically for my vision until I got visited by the lady who gave me the two canes I now use. My stroke was during covid, and I think it was difficult for people to know how best to help the sensory ophthalmic care was delayed for some time.” (Survey participant)

Retina UK research found that those diagnosed most recently (within the past 20 years) are most likely to have found about Retina UK from an internet search, while those diagnosed longer ago were signposted by a healthcare professional [Retina UK Sight Loss Survey 2022]. This highlights that blind and partially sighted people are searching for support, rather than being signposted at point of diagnosis.

This is in line with our survey findings. When asked if spoken to about support after their sight loss diagnosis 48% said yes. However, a relatively equal number said no (44%).

**Chart 1: After your sight loss diagnosis, did anyone speak to you about what kind of support is available and where? (n=423)**

“From my diagnosis, I also have to say at no point was I sent to sensory clinic or anybody that could point me in that direction of support.” (Focus group participant)

Awareness of what support is available often came from word of mouth, family, friends, or an internet search:

“But I'll be honest, I only actually found out that I could do cooking skills with them only (ROVI)… because a friend of mine had actually done mobility, but she was offered some independence cooking skills… and I was talking to her about it." (Focus group participant)

Participants reported having to find support themselves, without signposting, taking a proactive approach on gain help and support following their diagnosis:

“I did an awful lot of information searching myself, and because I did that, I have had a lot of really good help.” (Focus group participant)

This is further backed up the fact that self-referral was the third most common way into vision rehabilitation support.

**Table 1 has two columns and ten rows and shows breakdown of how participants were referred into vision rehabilitation support.**

|  |  |
| --- | --- |
| **Please tell us how you were referred to vision rehabilitation support** | **Proportion of sample (n=234)** |
| By a local NHS hospital | 33% |
| By a local eye clinic | 16% |
| I referred myself | 13% |
| Other (please specify) | 9% |
| By a voluntary or community sector organisation | 7% |
| By an Eye Clinic Liaison Officer (ECLO) | 7% |
| Don't know | 6% |
| By an optician or eye specialist | 6% |
| By my General Practitioner (GP) | 3% |

Additionally, participants spoke of a lack of clarity about the type of support that is available:

“And like I didn't even know you could just do that like I thought it just have to be mobility or something and then maybe you'll do some cutting and some peeling skills, which I don't need help, but it is more than knowing how to cook kind of thing, I’m fine with chopping and peeling, but, you know, maybe like reaching into the oven, things like that. And the temp like knowing about temperatures, what temperatures chicken should be when it comes out? Not a clue, so yeah, she said ‘yeah, you can go just for that’ and I never knew that.” (Focus group participant)

This lack of awareness, signposting and clarity of what support is available might explain why only just over half of our survey sample received support or training from a vision rehabilitation service (56%). For those who did not receive support, the main reasons cited were not being aware that support is available (58%) and having friends and/or family who are happy to provide support (24%).

**Table 2 has two columns and six rows and shows breakdown of participants who have received training or support from a vision rehabilitation service.**

|  |  |
| --- | --- |
| **Since your sight loss diagnosis, have you ever received any support or training from a vision rehabilitation service?** | **Percentage (N=423)** |
| Yes | 56% |
| No, but I am currently waiting for support | 2% |
| No, I have not received support | 35% |
| I was offered support but I did not want it | 3% |
| Don’t know | 4% |

### Harmful consequences of long waiting times

Our findings indicate that blind and partially sighted people are being put at risk due to long and inconsistent waiting times for support.

For both our survey and focus groups participants, waiting period from being diagnosed to referral varied from immediately, within a month, within one to three months, and over a year after diagnosis. For the blind and partially sighted people we surveyed, 27% of those who did receive support were referred for support a year or more after diagnosis.

**Table 3 has two columns and 6 rows and shows breakdown of how long participants had to wait after diagnosis for a referral.**

|  |  |
| --- | --- |
| **How long after diagnosis were you referred to vision rehabilitation services?** | **Proportion of sample (n=231)** |
| Immediately to within a month after diagnosis | 32% |
| Within 1 to 6 after diagnosis | 22% |
| Within 6 to 12 months after diagnosis | 6% |
| A year or more after diagnosis | 27% |
| Don’t know | 13% |

Participants in our focus groups also reported varied waiting times, with some saying it was between six and seven months before they were seen by their local authority’s sensory rehabilitation team:

“I contacted them because I just moved into a new house as well and I think I think it's through social services, so I'd go through the duty desk or whatever it is and then I was placed on a waiting list. It was quite long, though I think I was waiting since. So it was quite a few months, moved in October, then first session in May.” (Focus group participant)

“Then I had to wait six months to see a ROVI. I didn't really know what a ROVI particularly was at that point, but I had to wait about six months.” (Focus group participant)

Some people who had been referred to their local authority hadn’t heard anything at the time of the study:

“I have not yet received any help from the local authority but I have yet to contact them and they have not contacted me.” (Survey participant)

“There's adult social care. It's supposed to get in touch with me, I believe. Well, they're supposed to be getting in touch with me a few months ago, and I still haven't heard nothing from them” (Focus group participant)

Focus group participants told us of how they were not ‘waiting well’ and the consequences waiting times can have. One participant shared their experience of almost getting run over trying to cross the road whilst waiting for support. Another participant shared their experience of having accidents whilst trying to cook and highlighted that the support provided from the ROVI has prevented more accidents:

“I **nearly got run over**. This would be about six months later. I'm in tears. I phoned up the social services and said, you know, I really do need whatever it is that supposed to happen at this point and a couple of weeks later, the ROVI came out.” (Focus group participant)

“I wanted to be to actually cook something fresh and I wasn't able to do that, as I didn't have the skills at that point and then also my sight deteriorated to certain degree while I was waiting as well, to the point I can't actually see to use the hub like I used to… I **was basically burning myself more than usual**, like catching my arm on the in the oven and things like that, or touching the edge of the hob by accident, **burning my finger**.” (Focus group participant)

### Support is heavily focused on mobility

The most common type of training participants receive are long cane training (57%) and training in how to use relevant vision aids (39%).

**Table 4 has two columns and eight rows and shows breakdown of rehab training received by participants.**

|  |  |
| --- | --- |
| **Which of the following, if any, trainings have you received or are currently receiving? Select all that apply.** | **Percent of cases (N=231)** |
| Long cane training | 57% |
| Training in how to use relevant vision aids, adaptations, or equipment | 39% |
| Communication and associated technology training | 30% |
| Other | 30% |
| Daily living skills training (e.g. cooking, dressing, cleaning) | 27% |
| Mobility inside the home training | 25% |
| None of the above | 19% |

Despite this less than half of participants were confidently able to feel safer moving around outdoors (43%), feel safer moving around within the home (42%), and even less feel they can travel independently (28%) as a result of support received.

Moreover, only one in four feel they can independently complete daily living tasks, and half do not feel vision rehabilitation sufficiently addresses the emotional /psychological impact of sight loss. More concerningly, only 20% stated that they felt less lonely or isolated as a result of the support they received.

Focus group participants also touched on the lack of support with emotional or practicality of sight loss. One participant felt that professionals never connected the impact the condition with how it will impact an individual’s life:

“It would never have ever occurred to them to. I think knowing the team that I see don’t get me wrong. They’re very good at what they do. But they see you as a pair of eyes. Nobody’s ever acknowledged the visual, the sight loss on an emotional or practical basis. In any appointment I’ve had, it’s always been. Umm. Priorities for them has been my eye”. (Focus group participant)

**Table 5 has two columns and fourteen rows and shows breakdown of what participants are confidently able to do as a result of rehab support received.**

|  |  |
| --- | --- |
| **What participants are confidently able to do as a result of rehab support received** | **Proportion of cases (n=228)** |
| Feel safer moving around outdoors | 43% |
| Feel safer moving around within the home | 42% |
| Use communication and technology devices | 39% |
| Feel better about yourself | 37% |
| Meet and interact with people outside the home | 33% |
| Personal care e.g. eating, dressing, bathing | 31% |
| Manage your own health | 29% |
| Spend more time doing things you enjoy | 29% |
| Travel independently | 28% |
| Independently completing daily living tasks e.g. shopping, cooking, cleaning | 25% |
| Feel less lonely or isolated | 20% |
| None of the above | 9% |
| Maintain or find employment | 9% |

Participants also reported that the most frequent support and advice provided is benefits/financial advice (41%), while at the same time the least common advice received was managing personal budgets (5%).

**Table 6 has two columns and twelve rows and shows breakdown of types of support and advice received by participants.**

|  |  |
| --- | --- |
| **And which of the following, if any, types of support and advice have you received or are currently receiving? Please select all that apply.** | **Percent of Cases (n=231)** |
| Benefits/financial advice | 41% |
| None of the above | 34% |
| Other | 25% |
| Support with leisure/social activities | 23% |
| Emotional/psychological support | 22% |
| Housing advice | 12% |
| Managing medications | 12% |
| Employment advice | 11% |
| Support for family/carers | 10% |
| Out of hours support | 6% |
| Managing personal budgets | 5% |

There was a recognition of the benefit of different types of support, with people being generally open minded to support and advice being provided in a variety of ways and settings, provided support was actually there. Information was one of the key areas which was seen to be important as something that needs to be provided to a blind or partially sighted person at the time when it is needed:

“On the other thing is just information really, I think you can't get enough information and that's where I think services need to be giving people information at much earlier stage and so they can make choices and know what is available. rather than search for it themselves” (Focus group participant)

“I wouldn't wanna swamp people, but I think that actually knowing what your rights are. So rather than sitting at home twiddling your thumbs thinking I can't get out, knowing that you can put a little bit of pressure on you social services” (Focus group participant)

The role of the local authority and low vision clinics was then addressed. One participant called low vision clinics and rehabilitation services offered as the ‘bread and butter’ of support. Whilst there was recognition that this was positive, it was also remarked that this is the most basic entitlement, but that support needs to go further than that in order for a person with sight loss to thrive:

“What you might call statutory service that you get from the ROVI and the Low Vision clinic. They're really the kind of bread and butter. But you don't wanna live on bread and butter. Really. All the time. So I think they're good. And I think they cover most of the bases” (Focus group participant)

#### Long cane as invaluable

Various adaptations, aids and equipment were mentioned as part of the rehabilitation people received. Perhaps unsurprisingly, there was a lot of positive sentiment surrounding the provision (and use of) visual and mobility aids including long white canes, guide canes and symbol canes.  Guide dogs were also mentioned as a great support, enabling people with sight loss to get out and about.

However, some participants spoke of initially not wanting white cane training due to stigma, but later overcoming this resistance to training:

“And then said that we would do some white cane training, which I didn't want because I didn't want the stigma. But we did. We did do it and. I realized it was helping my balance, which was brilliant” (Focus group participant)

Those who received long cane training were happy with it once completed. One focus group participant spoke about how magical the cane is and how the training is essential, and the cane is now their superpower as it has given them a sense of independence.

The white cane also showed society that they have sight loss, as participants spoke about public perceptions of sight loss, with some members of the public commenting that they didn’t ‘look blind’:

“I think that the ROVI was the person who made most difference to me. Teaching me how to use the white cane revolutionized 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 it's a sign that there's something up with my eyes.” (Focus group participant)

“It had a massive impact on my confidence, to be honest. Just learning to use the cane. Umm, so there's a sort of take this side, but also the signal to other people because one of my problems is that I can't judge what other people are gonna do… really nice to feel that I can do is, yeah. Umm, there's stuff you know to be to go out independently” (Focus group participant)

“And I had a really excellent service from the ROVI for six months and did the white cane training was really grateful, really embraced that. So I couldn't fault that at all. It was fantastic.” (Focus group participant)

“Long cane as it enables me to continue getting out and about when I can’t work my guide dog.”  (Survey participant)

“It’s made significant difference to me having the cane actually because I'd lost completely lost my confidence going out.” (Focus group participant)

“It was had a huge impact on me… Just on itself is great for mental health. This after you know knowing I can go through that door when I know where I'm going, what I'm doing.” (Focus group participant)

However, when asked what equipment is most useful, the majority expressed that digital technology (including phones, tablets, computers and the magnification and screen reading technology that comes with them) was most helpful to their daily lives, as expressed by the participant below:

“Currently, my favourite magnifier is the one built into my Android phone.  I can read my own post, sign forms, read street and shop signs, read menus, read cooking instructions and medication information along with so many other things.  I couldn't do any of those things without it.” (Survey participant)

It is worth noting that all items carried positive sentiment and were regarded to be helpful with only a small minority of participants reporting little or no benefit from various aids, adaptations or equipment.

### Hidden support – the role of family and friends

A key theme in both the survey and focus group was the invaluable role that support from (sighted) family and friends play in enabling blind and partially sighted people to lead an independent life.

Family in particular appear to fill in the gaps in rehab provision identified earlier – providing a range of support from going out, cooking, cleaning, shopping, managing medication, and using connected devices.

“I always have someone with me when I go out.”

“I have adapted to doing these things myself or my wife helps me or does them for me.”

“I cook under supervision of wife. My wife does my medication. I never go out without the wifey.”

“Grandson helps me with mobile phone daughter helps with shopping cooking and cleaning.”

“I had very little help apart from the white cane training and I don't go out much on my own, my friends, daughters or mother come with me. I am content and happy with my limited horizons. [The] worse my sight gets I feel more tired.”

However, despite this, only 10% of participants who received support reported that this included support for family/carers. Moreover 42% of participants did not feel that family/carers are given adequate opportunities to be involved in rehab.

Another valued support was the role of peer support. Support from other people with vision impairment offered friendship and networking opportunities to people and was a key source of a range of support which may be unavailable through rehab. For instance, participants spoke of the emotional impact that being part of a group can have:

“Young person's meet up… they are a fantastic place because then make friends and just get out and **feel like a normal person**. To be honest, it's an exchange in tips and advice… I'd actually say that is one of the biggest places for young people where they do learn about things like services or whatever it is.” (Focus group participant)

“…Having support and building a network of people around you who are sighted impaired it's also made a big difference to me. And through them, being able to access things that I maybe not be able to access otherwise.” (Focus group participant)

“I would say support from other people in the similar situations is massive. There's been massive for me and because it's not about a competition, is there, but it's really heartening for me to hear somebody who's completely blind and what they're still able to do actually. And you know, so I'm less scared now, if that was different to me, I was sort of got a sense that actually it's gonna be if it happens, it's gonna be really hard. But you know, it doesn't mean my life come to an end.” (Focus group participant)

“You start talking to people and you realized that, you know, I really value my VI friends now. And I didn't realize until. Relatively recently, what a godsend they were, because we all do things in the same way. We understand it. Again, it's not rocket science. If you don't have good sight, you there are ways of doing things and you don't want people to move things around. You know you need to keep things in their place and you need to be able to advocate for yourself. Just giving you the confidence to be able to articulate that.” (Focus group participant)

### Those who can self-advocate find better support

The findings also indicate that if the person was prepared to push to gain the help and support, and to advocate for themselves, there was the potential to find good quality support. This implies that where support is gained, people with sight loss are benefiting from it – but that support is not easily found by those who cannot self-advocate:

“Yeah, you have to be assertive. You have to be an advocate for yourself and you have to push things otherwise you just not gonna get anything. But they're service I've had has been I mean the vision rehabilitation officer, absolutely brilliant. Really helpful and it's about I think it's about you know in this again very challenging world. We as the patient, as I have, 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's just terrible really.” (Focus group participant)

“I've had to be a bit proactive as to looking for the help…. I say found out about the Guide Dogs, you know children's team. Um, whoever I spoke to, she actually, you know, sat down and told me about all the other kind of support available not only from Guide Dogs, but from, you know, she asked do you know who your Rehab Officer is and would you like me to contact them or I can give you the contact into them. Or do you have you met the ECLO? Have you done this? Have you spoken to these people? And I gotta say, I was pleasantly surprised because I was expecting to have to do like my parents and have to find out every single detail myself. Contact everyone myself. But yeah, that's quite nice that at least. My experience with my daughter is a lot more positive.” (Focus group participant)

On the flip side of this positivity was the feeling of frustration and upset that support may not be available. 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:

“So, I think a big part of it was lack of confidence and frustration with the whole system 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.” (Focus group participant)

In some cases there was a delay in gaining support, and despite this delay, the individuals still had to seek out support themselves through charities such as RNIB:

“It's what I would say is it took [support], it was sort of felt like it was a long time coming and I had to access it off my own back or via the RNIB” (Focus group participant)

“All the emotional capacity to sort of work out what had gone on for about 3 months… that's when I started myself contacting people like RNIB, Glaucoma UK. And worked out for myself what support, things I needed.” (Focus group participant)

“Umm, I think that like a lot of other people have said, the RNIB have been an absolute lifesaver for me that they've signposted me to things this learning to live with sight loss course was massively helpful in terms of understanding that you know, cane, because I didn't think I met the criteria because I still have vision.” (Focus group participant)

“The [RNIB] Living Well With Sight Loss course. I only did that last year. That was absolutely wonderful.” (Focus group participant)

Some participants were concerned for those who not able to fight for support:

“So, you know, I'm somewhat concerned that that people that that aren't as confident don't really get a service and they really should be getting a service.” (Focus group participant)

In addition, only 19 per cent of our survey participants felt very well informed about what their rehab support would involve.

### Need for continuous support

There was a strong idea around continued support for blind and partially sighted people, beyond initial contact and rehab support (if offered). The idea that blind and partially sighted people’s conditions and situations are constantly evolving. From a change in eyesight, to moving area, and other major life events – additional and the idea of continued support was valued by participants within our focus groups:

“So I am constantly evolving and progressing and I think we all just need that help from local authorities, charities, whoever it may be, to just constantly evolve and you know, yeah, we can't do some things that we used to do, but there's plenty of other avenues and opportunities and really great things that we can do and contribute to society and we should be, you know, helped to do that.” (Focus group participant)

Along with a comment about moving area, one participant felt a general refresher in skills would benefit them and would offer them the chance to learn skills which they previously had not learnt in their rehab support:

“I think I would benefit from another ROVI appointment, particularly when I move area. It might be useful to refresh my skills and learn. You know, maybe there were further skills that I hadn't learned. But maybe also looking at. Any new house? I mean, if there are any adoptions that I need that sort of thing, so I think. I think it would be useful. I think that's quite a luxury when some people are not getting the first check in. But I think it would be good.” (Focus group participant)

Ongoing check ins on an occasional basis were thought to be a positive step which could help, through offering blind and partially sighted people a point of contact:

“I think checking in on people maybe? You know… just maybe a telephone call to see how you doing. Is there anything that you'd like to? I don't know who should do that, whether the ROVI or somebody in their team could do a phone call. I know that maybe even the RNIB. You know there's helpline there that. You could have a little conversation with them. So, I think maybe that would be a good thing for me to do that check on my mobility and my daily living.” (Focus group participant)

“Sight loss of touches everything. It's like spaghetti on your plate. And you just can't deal with one thing at a time. You know, because particularly for someone like me, that has still some useful vision, but I have no guarantees in the future. I wanna know everything. Now I want to learn now while I still have a bit of it. You know, a bit of sight. I want to future proof myself.” (Focus group participant)

However, it would appear that support is not often continued, with only 28 per cent of our survey participants reporting being contacted for follow up.

### Need for a ‘sight loss-informed’ provider

Within both the focus groups and survey, there was a range of ideas as to who should provide rehabilitation support to people with sight loss following a diagnosis. Whilst many suggested that national charities such as RNIB and Guide Dogs had a role to play within this process, most thought that the responsibility came down to either local authorities or in some cases the NHS:

“There is of course the area that's RNIB and other charities, so cover. That is all the support that the training on the teaching of new skills that's really vital. It's needed, but it's there. You do it and uh, I feel that charities cover a lot of that. Should be done by the government, but that's just a vision in the in the end of the never mind that where the support comes from, it has to be there.” (Focus group participant)

“It should be provided by organisations like Guide dogs and or RNIB or another Sight loss Professional as the local authority do nothing.” (Survey participant)

“Our local council should be the first place, unfortunately they don't know a lot about visual impairment. It should be a visually impaired organisation who will have knowledge & experience of knowing what visual impairment is, how to deal with someone who is visually impaired, most of all that they are sympathetic and understanding.” (Survey participant)

Some medical professionals aren’t aware that some conditions lead to sight loss and would rather focus on treatment for the condition, rather than providing support for sight loss, which can mean individuals are unable to live such an independent life they once lived, such as having to give up driving. There is a need to address the emotional and psychological impact of sight loss.

Concern that provision might be moved away from experienced ROVIs to more generic form, while this may be appropriate in some cases, participants spoke about the need for specialist support to help them with their sight loss.

“No one seems to realize that the fundamentally we can't get out unless we have a real specialist level of support. And there is a complete failure to acknowledge that. I think it's just terrible.” (Focus group participant)

“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 a walk, but she realized I needed specialist assistance from a from a low vision perspective. So that that was challenging.” (Focus group participant)

## Recommendations

It is evident that support and care post diagnosis is a postcode lottery which has been exacerbated by the Covid pandemic.

RNIB’s sight loss pathway mission is “from the moment someone realises that ‘something isn’t quite right’ with their sight, through to diagnosis and being able to live confidently with their condition, people have access to advice and support they need.” Our findings indicate that support is not triggered automatically, and it can be a considerable time after certification and registration before people receive support. Based on our findings we recommend:

1. **Improved awareness/signposting/access.** There is a need to improve access to support post diagnosis. Blind and partially sighted people tell us they are having to self-advocate for emotional and practical support. All medical staff should have visual awareness training, as there are many touchpoints during diagnosis where BPSP could be signposted to support.
2. **Tailored support.** Support when provided has been tailored to the individual and has helped them live a more independent life and reduced the risks of accidents. Confidence levels have also increased when receiving support and care, however waiting times can have an impact.
3. **Holistic support.** There needs to be a pathway which filters support throughout their sight loss journey as things are constantly evolving and changing and their needs may have changed. During the period of receiving support, BPSP are often coming to terms with their new identity as a person with sight loss, some may have had a sudden diagnosis whereas others may have had more time to come to terms with their diagnosis. Either way, support needs to focus on supporting BPSP accepting their new identity and help them navigate finding their ’new normal’.
4. **Rehab model.** A post diagnosis pathway needs to be systematic, automatic and patient focused. BPSP need to be awareness of the support available to them which can lead to them becoming more independent.

## Appendix

**Further sample detail:**

* 56% of the sample were women.
* 73% of people were from England, 13% from Scotland, 8% from Wales, and 3% from Northern Ireland.
* 62% were living with another disability or condition as well as their sight loss.
* 9% of the sample were from BAME groups.
* 64% of the sample were retired, 14% were unemployed, and 7% were employed.

## About RNIB’s research

RNIB is a leading source of information on sight loss and the issues affecting blind and partially sighted people. Our Research and Knowledge Hub contains key information and statistics about blind and partially sighted people including our Sight Loss Data Tool, which provides information about sight loss at a local level throughout the UK. You’ll also find research reports on a range of topics including employment, education, technology, accessibility and more. Visit our Knowledge and Research Hub at: **rnib.org.uk/research.**