

Produced in collaboration by

**R N I B**

See differently



# VI Lives

An in-depth understanding of the experiences of people living with vision impairment (VI) in the UK



Insight Angels

Research conducted by Good Innovation and Insight Angels

September 2022



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# Executive summary:

## Mindset is key

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▶ **A combination of V I and wider circumstances can have a profound emotional impact**

Most people living with V I have a positive mental outlook and want to keep growing by developing a resilient mindset and regaining their independence. However, a minority can find the combination overwhelming and sometimes lead to negative emotions.

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▶ **Diagnosis is a critical moment for most, but there's not enough information, guidance, or empathy**

More practical and emotional support, better signposting and quicker referrals are needed – this leads to a greater level of acceptance, lasting positivity and confidence when adapting to life with V I.

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▶ **The most important factor to improve quality of life is better accessibility to transport and public places**

Most adults with V I leave their homes frequently. However, a quarter feel they are not getting out as much as they would like.

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▶ **Social participation and exercise are vital to achieve a sense of accomplishment and maintain wellbeing**

Although around half of people living with V I are not able to take part in physical exercise, hobbies or social activities as much as they would like.

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▶ **Improving public awareness, understanding and empathy is considered a priority to improve quality of life**

Public understanding around V I in general and the range of sight conditions is very poor. General ignorance has often led to negative encounters.

▶ **V I people often feel cut off from employment opportunities and feel that little support is offered to them**

Nearly a third have difficulty stretching their household budget, and of the working age population, only 54 per cent are employed – this is even lower among the registered population. Changing the attitudes of employers is crucial.

▶ **Technology is a key enabler but there are huge disparities in awareness and access**

Technology has an especially critical role to play in helping people with V I in employment as well as in navigating journeys and public spaces.

▶ **A strong supportive network can play an important role in helping people to come to terms with their V I**

Most have people they can rely on if they need support but having V I can put pressure on personal relationships, and family and friends seldom get any support themselves.

▶ **V I charities can lack relevance and their services are poorly signposted**

More than half of people with V I said they have never contacted a V I charity. Barriers to engagement include a poor diagnostic experience and a perception that V I charities only cater for the completely blind.



# Foreword: Understanding V I Lives and enabling change



V I Lives is an important study that is designed to help the sector (and beyond) better understand people with V I, including those not currently engaging with the sector.

The traditional ways the V I sector has sought to understand people with sight loss – such as the severity of the V I or the length of time living with the condition – do not effectively predict how people feel or their ability to lead a fulfilling and balanced life.

Instead, differences in how people adapt and adjust to life with V I are intricately linked to their mindset – it's about resilience, attitudes to life and how open people are to the challenges V I presents.

As a sector, we need to increase our relevance and tailor our services to better meet individual needs by

considering attitudes, mindsets and resilience. We must also remain aware that mindsets are fluid and can change depending on circumstance.

This study provides a new way of understanding how living with V I feels and how blind and partially sighted people can adapt and lead fulfilling and balanced lives.

We hope that these findings will enable partners to better engage and serve blind and partially sighted people with relevant support, communication and services.

**RNIB, Guide Dogs UK and Thomas Pocklington Trust support V I Lives.**

Finally, a note about language. V I is used as shorthand for vision impairment in this report. Occasionally, it stands for vision impaired.



# Acknowledgements

**It is important to start by thanking the blind and partially sighted people who were involved in this study. Producing this report was a collaborative effort, built with the input and guidance of 800 blind and partially sighted people.**

Their insights provide a powerful insight into how we as individuals and organisations, working alongside blind and partially sighted people, can provide the support they require to participate equally in society and live independent lives.

Throughout the study, participants were treated as active co-creators rather than passive respondents, and we thank all of them for their willingness to share personal details of their lives. Quotes provided by research participants throughout the report are anonymous to protect their privacy.

We would also like to thank our Involvement Group of blind and partially sighted people – Steve Rattray, Ken Reid, James Hodgkins, Kelsey Dickman and Mick Spriggs – who gave invaluable feedback on the design of the research and with crafting the outputs. Finally, we would like to thank Graeme Douglas at the University of Birmingham for his invaluable input into the design of the questionnaire for the quantitative study.



# Introducing the research partners



Good Innovation is an insight, strategy and innovation consultancy that specialises in the third sector. Using experts in unearthing in-depth qualitative insight, Good Innovation helps to place the needs of supporters and beneficiaries at the heart of organisational decision making within charities.



Insight Angels provides transformational insights using quantitative research methods to drive change for its clients. This is shaped through collaborative working with clients and is brought to all of its work.

## Insight Angels



# 1. The objectives of V I Lives

We aimed to meet the following objectives in the research study and subsequent report:

- To listen to the voices of blind and partially sighted people living in the UK and build an in-depth understanding of their lived experience.



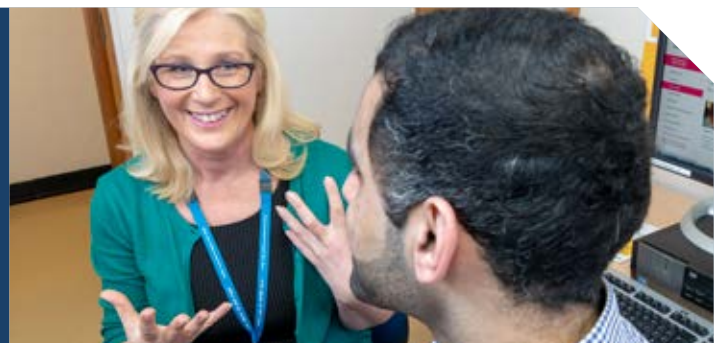
- To stretch beyond a traditional understanding of the impact of demographics and different sight-loss conditions by exploring attitudes, motivations and emotional needs.



- To use this deep understanding to uncover the gaps in support that are preventing blind and partially sighted people from living a fulfilling life.



- To co-create this study and report with blind and partially sighted people.



## 2. Methodology

The insights in this study were collected from a combination of quantitative and qualitative research with more than 800 blind and partially sighted people. All participants were recruited on the same basis of self-reporting a vision impairment that cannot be corrected by glasses – this was qualified through registration status and levels of difficulties in terms of functional vision (near, distance, peripheral).

For the quantitative study, 769 telephone interviews were conducted with blind and

partially sighted people, aged 13 and over and living in the UK, using a questionnaire designed to discover and understand their needs. To add emotional depth, nuance, verbatim and stories, the quantitative research was supplemented with 36 in-depth qualitative insight interviews and 18 week-long ethnographic studies.

This enabled the exploration of specific behaviours, mindsets and more complex topics in order to link them with support requirements and discover specific implications for service delivery.



# 3. Who we spoke to

Full sample details are included in the Appendix of this report. A high-level summary is below:

## Age profile

- Ages ranged from 13 through to 85.
- Two thirds of our participants were aged under 64.
- While those aged 75+ were under-represented in our sample compared to the overall population of blind and partially sighted people, we used weighting to make the age profile of the sample more representative.

## V I profile

- 50 per cent of the sample have a mild V I
- 31 per cent of the sample have a moderate V I
- 19 per cent of the sample have a severe V I
- Over half (54 per cent) of the sample have lived with V I for five years or more and 8 per cent since birth.
- We covered a wide range of V I, and found that Cataract, Age-related Macular Degeneration (AMD) and Glaucoma were the most frequent.
- 17 per cent of our sample are registered severely sight impaired, 26 per cent are registered partially sight impaired, 4 per cent are registered but don't know the category and 53 per cent are not registered sight impaired.



## Other facts about the sample

- We spoke to people in all of the devolved nations.
- On average, participants have lived with V I for 21 years.
- 10 per cent of the people we spoke to were from BAME communities.
- Previously we have tended to focus research on the registered population, but this study aims to represent the approximately two million people living in the UK with V I.
- However, we recognise that the research is likely to exclude the 800,000 people who have an uncorrected refractive error and are unlikely to identify as having sight loss.



## 4. Introducing a new emotional dimension

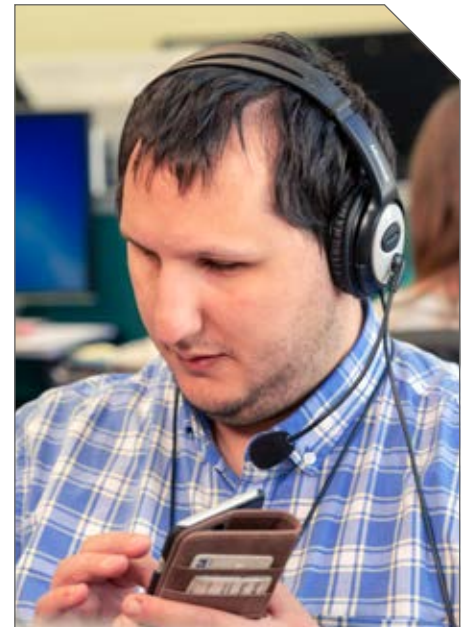


Traditionally, the sector has sought to understand the blind and partially sighted population based on facts about their vision impairment. For example, the severity of their V I, the length of time they've been living with condition and the life stage they're currently in. While these dimensions can be useful, our research found that they do not effectively predict how people feel and their ability to lead a fulfilled and balanced life.

Through this research, we explored other dimensions to understand how people feel and ultimately when and how they may seek support. We found that blind and partially sighted people adapt to their conditions in different ways when their emotional responses differ. Subsequently, communications and services must be tailored accordingly. Different attitudes, mindsets and levels of resilience mean that "one-size-fits-all" solutions do not work.

We uncovered some key insights that unite people living with V I in the UK and frame the findings outlined in this report.

# 5. Life with V I



People living with V I find daily life presents many challenges and, although some struggle to cope, participants presented a sense of determination and pride in their accomplishments. Whilst many have a positive outlook on

life, our research highlights a variety of needs that the sector can address to improve quality of life. This section of the report will look into these needs, enablers, barriers in detail and outline key considerations for the sector.







# 5.1 Navigating the external world

Ultimately, the needs of blind and partially sighted people are focused on the fundamentals. The most important factor to improve quality of life is better accessibility to transport and public places. Most adults are leaving their homes frequently – at least every other day.

- However, a quarter (25 per cent) feel that they are not getting out as much as they would like.
- This increases to over a third when we look at those with a moderate or severe V I and to 43 per cent when we look at those aged over 75.
- A third said they were unable to use public transport as much as they would like.

A third of people said it was extremely important to reduce street clutter as it affects mobility.

- 30 per cent claimed to have been injured in the last year by something they have bumped into. This does not vary dramatically by V I severity.

Navigating external environments is critical to a sense of independence, but public transport remains inaccessible and a key source of frustration. It is a universal truth that blind and partially sighted people are more likely to be

nervous about journeys and new environments, so they plan extensively to avoid problems. Helpfulness of staff, availability of assistance, lack of clear signposting, announcements and unmanned stations make transport extremely difficult to navigate and deter blind and partially sighted people from leaving their homes independently.

People with lower confidence and who haven't adapted to their conditions are often concerned about their safety when crossing roads, which limits opportunities to go out alone. They often report having a heightened awareness of the lack of accessibility aids and devices built into public domains.

**“ I don't like buses; I've not had any positive experiences with bus drivers – they're in such a rush and aren't that bothered. Once I got on with a friend and they shut the door halfway on me and didn't apologise. I avoid buses unless I absolutely have to. I'll get my wife to drive me instead.”**



“ I pre-book tickets, my seat and the passenger assistance. I take my own food and drink, so I don't have to navigate buying food on the way. I don't drink too much so I don't have to work out how to use the toilet on the train and don't have to ask for help.”

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The search for independence means people rely on portable devices, phones and apps to navigate journeys and public spaces. Accessible apps like Trainline enable and improve the quality of the journey but they are not suitable for all and don't cover all needs. Other confident blind and partially sighted people use more sophisticated technology and watch YouTube videos ahead of journeys to spot hazards.

“ I use Citymapper which will suggest different routes, has a rain safe mode, flags disabled access, and has really clear instructions.”

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“ I worry that I'll slip in the rain and if I want to go out, I use rain safe mode even if sometimes it takes longer.”

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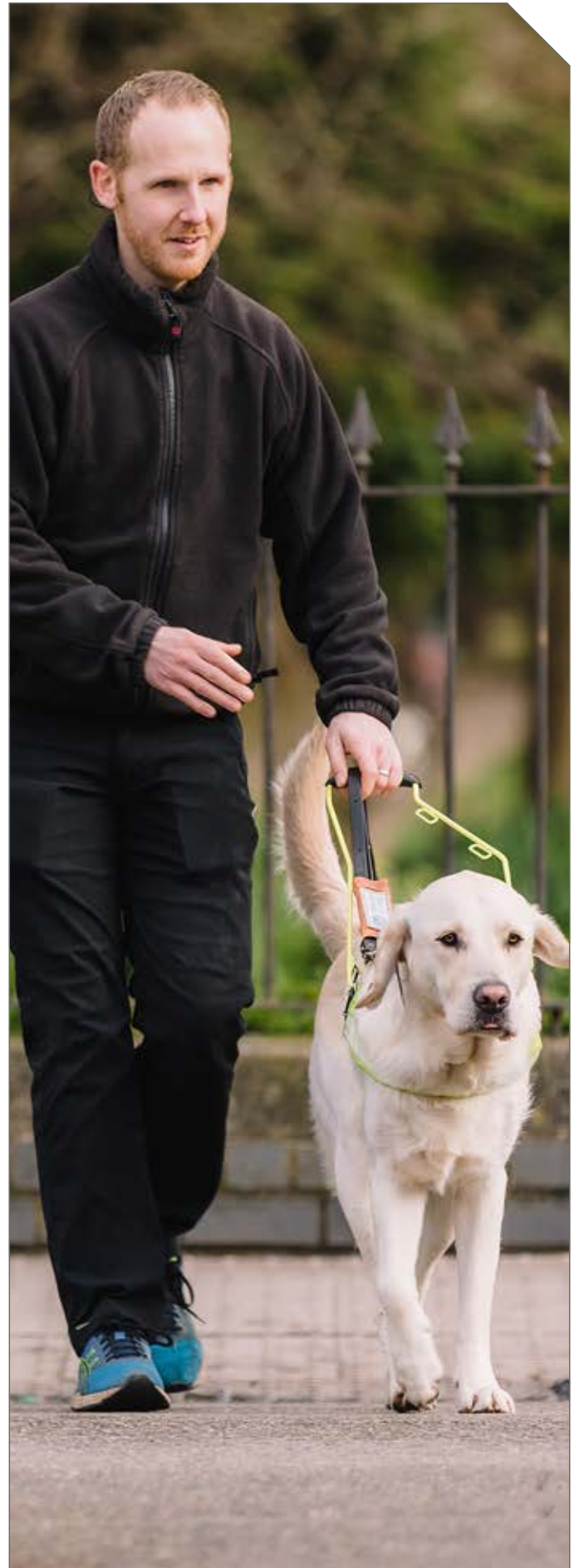
“ I didn't know for years that there's a disc underneath pedestrian crossings that spins to let you know when you can cross. Someone told me recently.”

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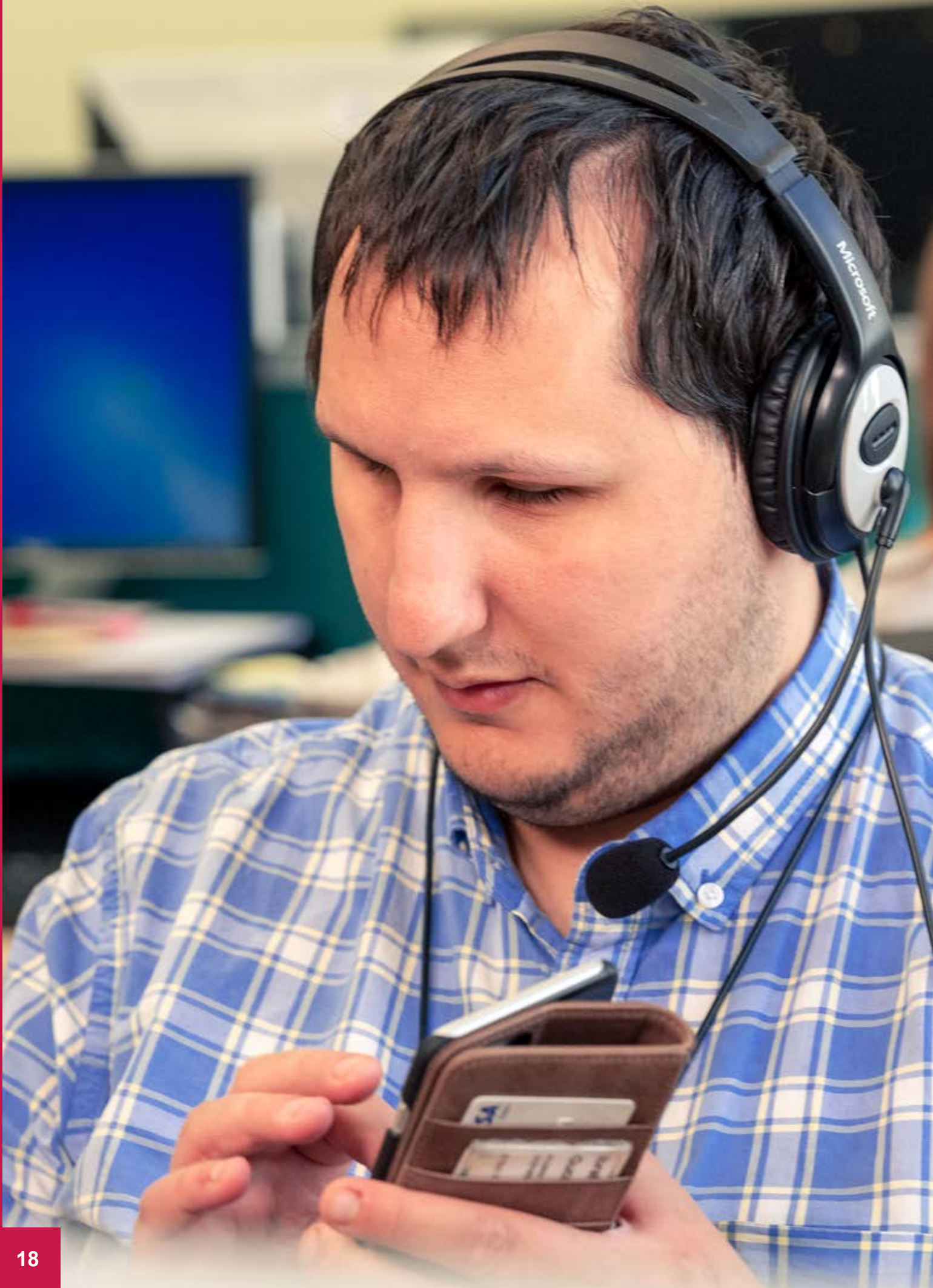
## Sector considerations

**As a sector, we must think about the following:**

- How can the sector empower blind and partially sighted people with the confidence and functional support, such as tools and techniques, to leave their homes?
- How can the sector influence the process for referrals into social care to ensure that people receive timely access to high-quality rehab services?
- How can we encourage blind and partially sighted people to develop the confidence and self-reliance to learn for themselves how to get out and about independently?
- How can the sector be at the forefront of technology developments that enable blind and partially sighted people to independently and safely navigate the external world?
- How can we persuade government and transport companies that the ability to make independent journeys is a right not a privilege, and that all services should be made fully accessible? For example, spoken announcements on buses.
- How can we lobby for or provide training for staff – such as bus drivers – on recognising and accommodating people with V I?
- How can we influence designers of the public realm to ensure streets and public buildings are accessible and clutter free?







## 5.2 Employment and income

Of the working age population, only 54 per cent are in employment.

- 11 per cent are unemployed, 12 per cent are long term sick/disabled and 8 per cent retired (early).
- 8 per cent are studying.
- Employment rates are even lower among the registered population.

Schemes set up by charities and the government to help find employment have not been used by four out of five people.

- Of those who are employed, only 14 per cent claimed to have received support under the Government's Access to Work scheme and 6 per cent were unaware of it.

Improving the attitudes and understanding of employers is a key dimension that blind and partially sighted people expect to be addressed.

The next most important workplace priority is availability of specialist equipment, followed by support in applying for jobs and interviews.

- It seems that assistive tech and workplace adjustments are more commonplace than flexible working hours and provision of a support worker.
- Two in five people told us no adjustments had been made by their employer.

Financial stability is a high priority, however nearly a third have difficulty stretching their household budget.

- Two thirds of those we spoke to claim they can make ends meet. However, nearly a third have difficulty stretching their household budget.
- 55 per cent of people receive a disability-related benefit however, of those who do, a quarter (25 per cent) don't feel it covers the extra costs that they incur because of their disability.

Blind and partially sighted people often feel cut off from employment opportunities and believe their aspirations are significantly affected. Job searching can be an intimidating process, which can result in pessimistic attitudes for some. Specific barriers to seeking work often include practical limitations like proximity and transport, no understanding of the types of roles that can be fulfilled by someone with V I, a lack of personal confidence around capabilities, fear of embarrassment and failure, and a sense that they'd be discriminated against in the workplace. Blind and partially sighted people expect a clearer pathway to employment and training with more disability-friendly employers, but these need to be more easily identifiable. Employment is a huge contributing factor confidence, sense of independence and overall quality of life. As such, more needs to be done to

help blind and partially sighted people sustain employment.

**“ I never wanted to do anything for a career... I guess I never let myself want it because I knew my limitations.”**

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**“ I’ve never really tried to get a job. I’ve done bits of DJ work over time. An actual job – I find that quite intimidating in a way. It’s knowing what job I’d actually be suited to do – I’d love to work in music. Even just working in a shop or office – I don’t feel comfortable with. A big part is finding what I’d be suited to do with my eye condition. A lot of blind people I know who have jobs mostly work in IT with a screen reader – I can use one but I’m not that literate in computers, so it’s not suited to me. I need help finding the most suitable opportunities.”**

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Blind and partially sighted people often feel they must fight for whatever support they receive – very little is presented or offered to them. They must explain their needs and provide solutions at every

turn, whether that is in their job, or further education. They take it upon themselves to look for adaptations and technology so they can continue working without diminished responsibilities.

**“ After a while of sulking I decided on what to do for the future – I needed to retrain. I looked for training courses and found that very difficult. No one knew what to do with me. I was very determined, but it was frustrating. I had to fight for everything at every turn. I felt angry; it should be them helping me, not me having to fight for it. Eventually, as my situation deteriorated, I had to drop out of my course entirely.”**

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Technology is a key enabler for people who have confidently adjusted to their V I and are driven by their career aspirations. They use technology in a more sophisticated way and credit it with giving them confidence and agency in the workplace, making it possible to continue to excel in their careers. Subsequently, they are more likely to be passionate about increasing representation and equal access to opportunities. They do this by leading workplace disability networks or campaigning for better accessibility and more inclusive workplaces.



## Sector considerations

**As a sector, we must think about the following:**

- How can the sector guide blind and partially sighted people on their first steps to employment by educating them about their rights, and what solutions are available to them – such as tools, supports and grants for training and equipment?
- How can the sector broaden blind and partially sighted people's career expectations by highlighting the wide range of roles that others with similar conditions are employed to do?
- How can we help blind and partially sighted people communicate their accessibility needs to others, so that employers can understand the adjustments they need to make?
- How can we provide the support needed to help people stay in work as their sight deteriorates?
- How can the sector continue to influence and drive development of accessibility features in mainstream technology that cater to the needs of blind and partially sighted people in the workplace?
- How can we improve access to support, tools and technology to help people thrive in the workplace and progress at the same pace as sighted peers?
- How can we encourage employers to recognise the benefits of diversity in the workplace and commit to making their culture, processes and environments more inclusive and accessible?
- How can we educate employers about how they can unlock the potential of blind and partially sighted people by making modest adjustments in the workplace?
- How can we convince employers of the business case for retaining an employee who is losing their sight so that the business can continue to benefit from the skills, knowledge and relationships the employee has developed over time?
- How can the sector offer blind and partially sighted people volunteering and apprenticeship opportunities to give them valuable work experience and the chance to learn new skills?
- How can the sector bring about equality of opportunity in the workplace so that blind and partially sighted people can achieve their potential?
- How can the sector support people to navigate the complex benefit system, so they receive the benefits they are entitled to and are able to claim Access to Work?



“ First thing I did was walk the route a few times. I usually run with a reflective jacket and if it’s darker I run with a light as well. I have to take it very seriously.”



## 5.3 Social connection and participation

Although other factors, such as mobility and employment, are considered a higher priority to improve quality of life, social participation and physical activity are still extremely important for a person's wellbeing.

- Over half are taking part in social activities as much as they would like but a third say they can't take part as much as they would like.
- A further 11 per cent say they can't take part.
- Those with a severe V I and those who are of a younger age profile are more likely to want to connect with like-minded people and are looking for more opportunities for sporting or leisure activities.

Connecting with other blind and partially sighted people and finding social activities to participate in is important to achieve fulfilled lives, but only two in five say they are able to participate as much as they would like. People who are struggling to adapt, lack the confidence to seek out and participate in social activities or engage in exercise or sport. They often resign themselves to minimal exercise and sport, or hobbies they can do alone. Sometimes this can result in a loss of friendships associated with those activities.

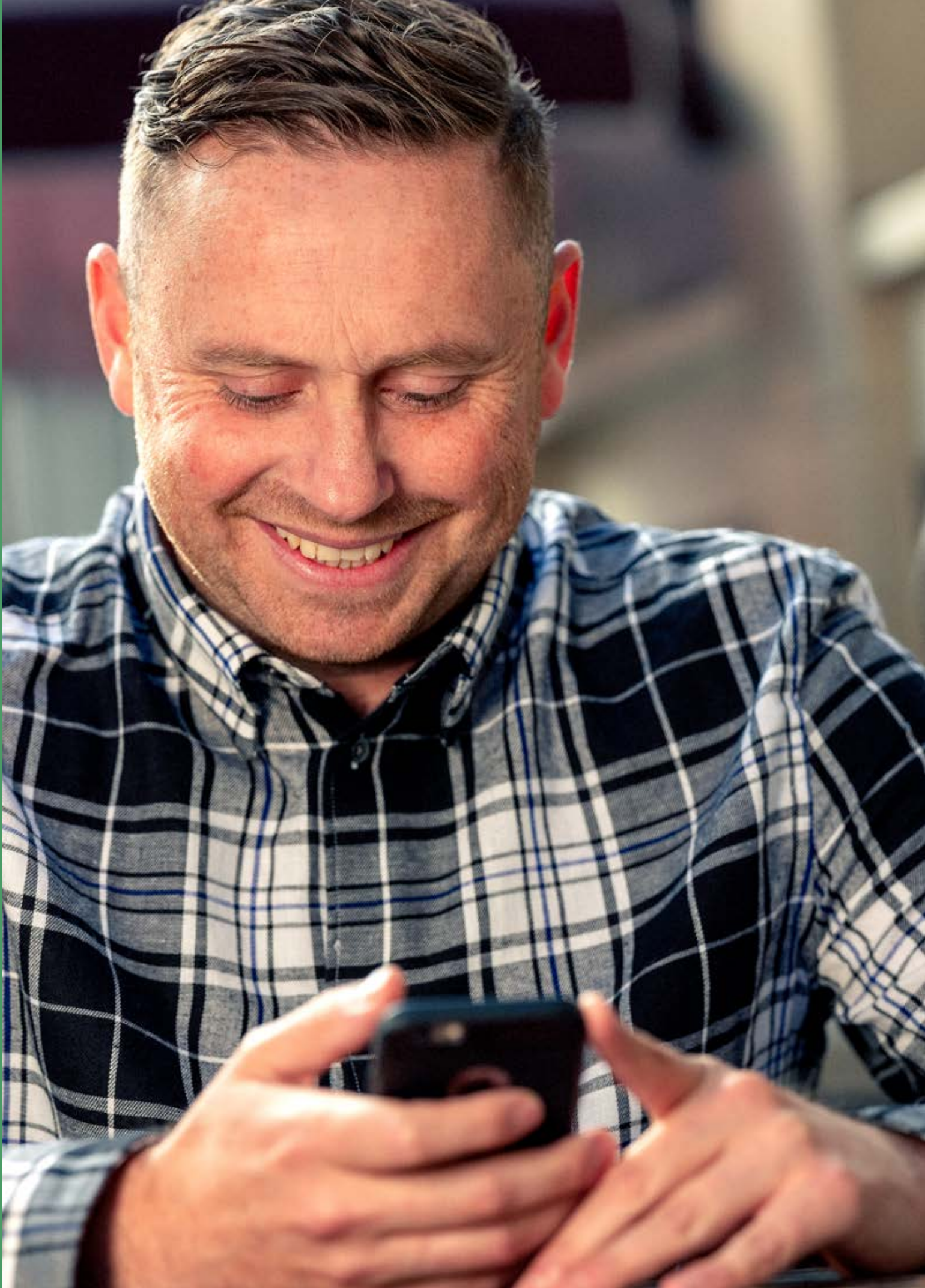
Blind and partially sighted people with more positive, resilient attitudes are looking for social activities to participate in to create a sense of accomplishment. Engaging in sport can be difficult and it's something that is fondly missed – as a form of exercise and social activity but also for the mental health benefits. However, in this mindset, people are less likely to dwell on activities they can not do and look for solutions or alternatives, such as tandem cycling.

### Sector considerations

**As a sector, we must think about the following:**

- How can the sector facilitate and better signpost existing social, leisure or sporting opportunities and groups for people to get involved in and support the development of peer-to-peer connections?
- How can we lobby for improved accessible facilities for blind and partially sighted people and highlight those that are already accessible?
- How do we do this inclusively to ensure teenagers and young people are able to connect and enjoy social activities relevant to their age group?





## 5.4 Tools and technology

Large sized text (both digital and print) is the preferred way to access information, however audio is also favoured, especially among those with severe V I. Only very few people use braille.

- Kindle and iPad screens can be enlarged, helping blind and partially sighted people retain independence and continue to read.

Around a quarter of people get help with printed material when it isn't in their preferred format, this support increases to half when we look at those with severe V I.

Two thirds access the internet every day, but as many as one in five never go online.

Smart phones, tablets and laptop/desktop computers are the most commonly used devices to access the internet. While younger people typically use a smartphone, over 75s are most likely to use tablets.

- A third do not make any adjustments when using the devices.
- Nearly half use magnification software.
- 19 per cent use screen reader software and 18 per cent use virtual assistants such as Cortana or Siri.
- Less than 20 per cent use voice recognition software or colour adjustments.

- Those with severe V I are more likely to use screen readers, virtual assistants and voice recognition software.
- Accessing V I-specific apps is very infrequent in comparison to mainstream browsing.





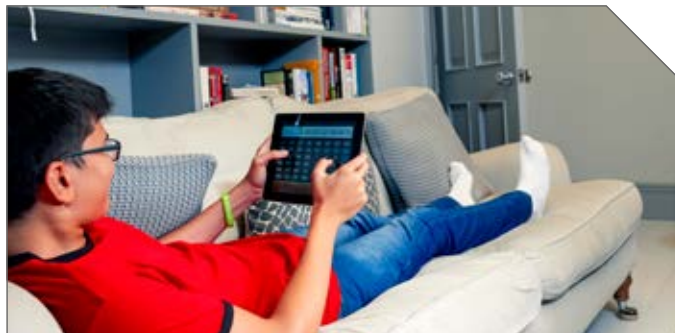
Those with severe V I are embracing more of the ‘smart technology’ available such as smart speakers, smart watches, virtual assistants and voice recognition software.

Devices are used for a wide variety of different activities including calls, emails, social media, browsing and online shopping. Accessing specific V I apps is actually a much less frequent activity. For those who have started adopting certain apps, iPhone is generally the preferred brand as it is more accessible, user friendly and relieves concerns around safety and security.

Technology is a key enabler but there are huge disparities in awareness and access. Many credit devices, such as the Amazon Echo, for enabling them to lead independent lives. However, many are totally unaware of the available apps, technology and specialist equipment that can make their lives easier and help them to adjust. Some are still in a state of denial and are managing with bright lights and magnifying glasses, but they are less motivated to seek out technological solutions.

“ Learning more about the computer was good; so the tech I use is a talking computer, reads my emails and so on. I can download books, read them.”

More technologically-proficient people rely heavily on assistive apps and technology both in and out of home, and they dedicate time and effort to



sourcing the right technology to make their lives easier.

“ I spend a couple hours a week looking at new tech available to find things to help me. RNIB is usually the website I first go to but when you look at Australian or American charities they have other things. I try to find the best bits from all over as some tech is available in other parts of the world and not here. I don't want to limit myself to just RNIB but it would be great to have a one stop shop.”

“ Apple products rule the house, as well as Amazon Alexa. Heavily deal with technology. I tried Android for a year and I was so happy to get rid of it, I find that it was more complicated to make things bigger. Apple is very simple.”



## Sector considerations

**As a sector, we must think about the following:**

- How can the sector influence and drive development of accessibility features in mainstream technology that specifically caters to the needs of blind and partially sighted people?
- How can we reduce digital exclusion by promoting the benefits of technology and encouraging blind and partially sighted people to take the first steps to get online?
- How can we ensure blind and partially sighted people have access to the advice and support they need to give them the confidence and skills to use technology to its full potential? How can we encourage mainstream providers to offer this expertise, so support is available where people need it?
- How can we facilitate peer support to enable people to share their experiences and support each other with technology queries?
- How can we provide opportunities for people to discover and unlock the full accessibility potential of mainstream devices?
- How can we make sure technology is financially accessible to all blind and partially sighted people?
- How can we support the ongoing development of specialist assistive technology and raise awareness of what's available?







## 5.5 Societal perceptions

Improving public awareness, understanding and empathy towards people with V I is a top-ranking factor to improve quality of life. 46 per cent agree the general public is often prejudiced against people with V I and 38 per cent have experienced discrimination. Public understanding around the breadth of sight conditions, including 'V I' and differing levels of adaptation, is very poor. General ignorance has often led to negative encounters with the general public, which can be damaging to the confidence of blind and partially sighted people, and make them feel cut off from society. This is true for even the most independent person.

“ I fell over and hurt myself and I felt stupid because everyone around you doesn't know you have sight loss, it's frustrating. People ask really personal and intrusive questions. It does build up after a while.”

“ People are ignorant. They tell you just to get glasses and stop being vain. They don't understand that if you're partially sighted, glasses won't fix it.”





Interactions with the general public are easier if there's a visual symbol of someone's condition. The public are more understanding when they can identify disabilities, but using visual symbols, such as a long cane, requires a level of acceptance for many blind and partially sighted people. People who are still adjusting to and learning to accept their V I, still feel that symbols, such as a cane, creates a sense of 'otherness'. However, a guide dog evokes a more positive response because they help people connect with the world around them and make them feel less isolated. The public immediately identify their V I and make allowances in a more friendly and welcoming manner.



“ Menus always have a really small font and waiters don't give you enough time to read. They keep asking and have no patience, and it's really annoying. You feel a bit rushed and nervous.”

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“ I don't have a white stick or visual symbol so if you look at me you wouldn't know... it's a hidden disability. People will assume that I am rude or ignorant or unfriendly. I haven't got a stick and I haven't got a dog. I need a sticker.”

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“ People don't know I have an impairment, so I don't think I'm perceived differently. The problem is that people say hello in the street and I can't reply as I don't recognise them. I'm a sociable person and this is frustrating – I don't want to offend them.”

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## Sector considerations

**As a sector, we must think about the following:**

- How can the sector educate the public about the broad range of vision impairments, building greater empathy towards blind and partially sighted people and a better understanding of what they are capable of?
  - How can we encourage greater acceptance that blind and partially sighted people might do things differently – such as using a magnifier in public – and use this to stimulate greater interest and curiosity into their experiences?
  - How can we encourage blind and partially sighted people to tell their stories to build greater empathy and understanding among the public?
- How can we support blind and partially sighted people to overcome the barriers to using signifiers such as a white cane and recognise how these can potentially unlock positive support from a well-meaning public?
  - How can we encourage behavioural change so that blind and partially sighted people don't experience negative encounters with members of the public?
  - How can we educate the public without using communications that present blind and partially sighted people as 'overly-needy' but empower them to feel comfortable asking the public for support or reasonable adjustments?
  - How can we encourage mainstream media and culture to improve the representation and profile of people with V I and portray positive role models?







“ The specialist looked at me and said “You’ll go blind in four years”, and then just walked out. I was stunned. I turned to my wife and said: “Did he just say what I think he said?”

## 5.6 The V I Journey

There is not enough information, guidance, empathy or support at diagnosis – arguably the most defining moment for most. When reflecting on the diagnosis, there was a lack of understanding of the impact their condition will have on their lives, what support is available to them and how to access it. Generally, this leads to a sense of denial at first and many reject specific services, meaning more people struggle for longer. This initial transition after diagnosis is the most difficult and people expect there to be more practical and emotional support from medical professionals, alongside more obvious signposting and quicker referrals to social care and V I organisations. Cases where this had been provided often led to a greater level of acceptance, lasting positivity and confidence adapting.

**“ I didn’t get told of anything that was available, any support, when I was diagnosed. It’s only because I had a friend who worked for one of the local charities for the blind that I found out anything at all.”**

### Sector considerations

**As a sector, we must think about the following:**

- How can we encourage health care professionals to recognise the emotional impact of a diagnosis of sight loss and deliver the news with empathy and understanding?
- How can we influence health and social care professionals to provide information and ensure they are referring people to the support they need?
- How can the sector effectively communicate and signpost the full range and breadth of services available to blind and partially sighted people?
- How can the sector provide ongoing information, advice and support to build people’s confidence and better prepare them for the future?
- How can the sector ensure it takes an inclusive, targeted and proactive approach to communications so that it is seen as relevant for anyone experiencing V I?
- How can we, as a sector, develop and innovate the range of products and services we offer to reach a wider range of blind and partially sighted people and address the issues they face?





## 5.7 Attitudes to V I and emotional resilience

Overall, blind and partially sighted people have a positive outlook, but for a minority, the combination of their V I and their wider circumstances can be overwhelming and sometimes lead to negative emotions.

How a person adjusts to living with V I is intricately linked to their mindset – it's about resilience, attitudes to life and how open people are to the challenges having V I presents.

Everyone responds differently. In fact, attitudes can differ significantly between two people living with the same V I

– impacting how they participate in society and how fulfilling a life they lead. The lower someone's levels of confidence and resilience are, the less adjusted they are likely to be and the longer they are likely to struggle.

It is worth stressing that mindsets can vary depending on changing circumstances, from day to day and even task to task. Blind and partially sighted people are not fixed in one emotional territory but move in and out of them as different factors combine. We explore the full range of emotional responses below.

### Periods of difficulty and frustration

In the earlier stages of adjusting to V I, people are often in denial and need help accepting their condition. They're frustrated by the changes they're having to make to their life, sometimes resisting them and struggling through. For others, it fuels a determination to explore how they can make changes to improve their quality of life.

Living with V I can be difficult and result in feelings of frustration, isolation

and anxiety in daily life. 40 per cent are struggling to come to terms with their V I and 67 per cent say they frequently think about their V I and the impact it has on their lives. Their fear and feelings of anxiety can lead to an overall sense of risk aversion, and a constant weighing up of risk in every situation. There's much more forethought required, and it can impact their ability to relax and enjoy situations. In fact, 56 per cent said they feel anxious about the future, and 52 per cent said they seldom feel relaxed.

Over a quarter feel angry and overwhelmed, and a small percentage of our participants have negative feelings with 8 per cent feeling ashamed and 14 per cent feeling rejected.

**“ Now every single day I wake up to the question ‘can I see’? The psychological damage is done. If I’m sleeping and wake up, I must have light so I can make sure I haven’t gone blind in the night. It’s an everyday worry.”**

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**“ I train myself to use my other senses – I am preparing for the worst; I think about what could happen and adapt and learn whilst I’m able to.”**

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Many blind and partially sighted people are also likely to worry about their future and fear that their sight will deteriorate, making them more dependent on others.

Although 72 per cent feel frustrated with their V I and 53 per cent are worried, blind and partially sighted people often internalise the toll it is taking. They don’t confide in anyone and thus have not received the emotional support they need – formal or informal.

A fear of burdening loved ones with ‘more’ or being perceived as ‘complainers’ stops them from

communicating their emotional needs to anyone, only further slowing down their adaptation to their V I. During in-depth interviews, many participants pointed out that this was the first time they had confided in anyone, processed their emotions, taken time to think about the impact on their wellbeing, and considered that they might need additional support. For most, it was extremely cathartic. Ignoring their emotional needs can lead to a feeling of overwhelming loneliness and for some it can lead to more serious mental health problems, such as anxiety or depression.

**“ On this journey, not one single person has offered psychological support. I would have liked this on how to adapt and cope with my changing sight. I carry this trauma with me that I have to have a light on to make sure I can see.”**

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When striving to live independently, people are more likely to describe themselves as resilient but may suffer in silence. 47 per cent feel isolated and cut off from other people. They are less likely to actively seek out support because their biggest fear is becoming completely reliant on others. Although there are moments of frustration and feeling hopeless, they are more likely to try things, such as making journeys on their own first, because they are willing to learn from trial and error. They don’t want to ask for help as a default.



**“ Sometimes I just close my eyes and walk about the house and see what it feels like and touch things to make sure I know where everything is. I mentally prepare myself for the worst even though I don’t want to recognise it.”**

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Despite a general sense of stoicism, a blind and partially sighted person’s confidence can be fragile, and small practical setbacks can have a noticeable impact on one’s emotional wellbeing. For people adjusting to life with V I, they must rebuild their confidence and fight a persistent level of anxiety as they complete daily tasks, especially at home. Unsurprisingly, those with the most severe V I agree that they always or frequently need support at home, especially with DIY and cleaning.

**“ My level of anxiety depends on how the day is going. If I’m brushing my teeth and drop my toothbrush, my anxiety will be bad for the rest of the day. I try to do things to control my anxiety such as breathing, but I always have it now.”**

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## Periods of determination and growing acceptance

Despite high levels of frustration, most blind and partially sighted people accept their V I, and more than half feel optimistic and confident.

- 83 per cent feel accepting and 79 per cent feel determined.
- 56 per cent feel optimistic and 54 per cent feel confident.

On the whole, V I people, irrespective of V I severity or age, have a positive mental outlook on life.

- 84 per cent claim to have been able to make up their own mind about things often or all the time.
- 75 per cent agree they have been thinking clearly.
- Over half agree they have deal with problems well, as well as feel close to others and feel useful.

**“I’ve had to constantly adapt as my health has got worse. It’s a case of being able to do things, but not enjoying them quite as much. We love to sail. It’s quite difficult, but we adapted. It has hindered something that I love and that we would have done much more frequently if my sight hadn’t been an issue.”**

**“The only way I can see things getting better is if I can deal with it better. I’m afraid of getting into the “woe is me” mindset – and I do this by keeping busy and working.”**

Over time, people become more accepting and build a more resilient, forward-looking mindset because they are determined to live an independent life and not let their V I define their sense of identity.

Everyone we spoke to agreed it is important to grow and evolve in life; they see their V I as part of them and feel supported by others. 82 per cent agree that they are happy that they are making the most of their life.

More confident and well-adjusted people talk about V I as something they ‘have’ rather than something they ‘are’ and go out of their way to prove it doesn’t inhibit them living a fulfilling life. 92 per cent agree their V I is part of them and 84 per cent feel able to discuss their V I without getting upset. They tend to have a more optimistic attitude because they have become accustomed to using their strategies and aids.

Smart use of technology, reliable support networks, the ability to socialise and be independent, as well as workplace inclusion and employment opportunities all contribute to a greater



sense of confidence. These enablers are integral to a person's wellbeing and emotional resilience.

Although people are aware of the life experiences they may have missed out on as a result of their V I, they also recognise all the opportunities and perspective they have gained as a result. They tend to have clear career goals and personal aspirations and are often more determined to meet these as a result of their V I. In fact, some feel like they thrive off the challenges that come with having V I and they celebrate their achievements and accomplishments with a great sense of pride.

**“ I then discovered many other things that I'm good at, my eyesight doesn't have to limit me or define me... I knew that I had to compensate intellectually as I couldn't do things physically as well as other people and it helped me to develop and invest more time in education.”**

Those with a more confident and resilient attitude are not willing to attribute any mental health struggles to their V I. Although they might be aware of the emotional support available, they don't see the need for it. They focus on exploring new opportunities, rather than dwelling on those they may have missed.

## Sector considerations

**As a sector, we must think about the following:**

- How can we raise awareness among health and social care workers of the ongoing emotional strain of living with V I and highlight the need to refer/signpost people to the appropriate emotional support services?
- How can we make emotional support options – ranging from peer-to-peer connections to professional support – more directly available to people so they can build their emotional resilience, confidence and acceptance?
- How can we facilitate people to share first-hand experiences and learn from the experiences of others by connecting them with more resilient and well adapted blind and partially sighted people? How can we offer this in a way that feels relevant to different groups – offering connection points and forums that offer a range of times, ages, geographies and technologies?
- How can we provide better support for family and friends by giving them the tools to understand the emotional struggles their loved one is going through, thereby encouraging them to be open and remove the perception of being a burden?





## 5.8 Personal relationships

Overall, most have people they can rely on if they have a problem and need support. 78 per cent of everyone we spoke to have three or more people they can rely on. That support overwhelmingly comes from their own network, with 89 per cent naming a family member or friend – most frequently their partner or a child.

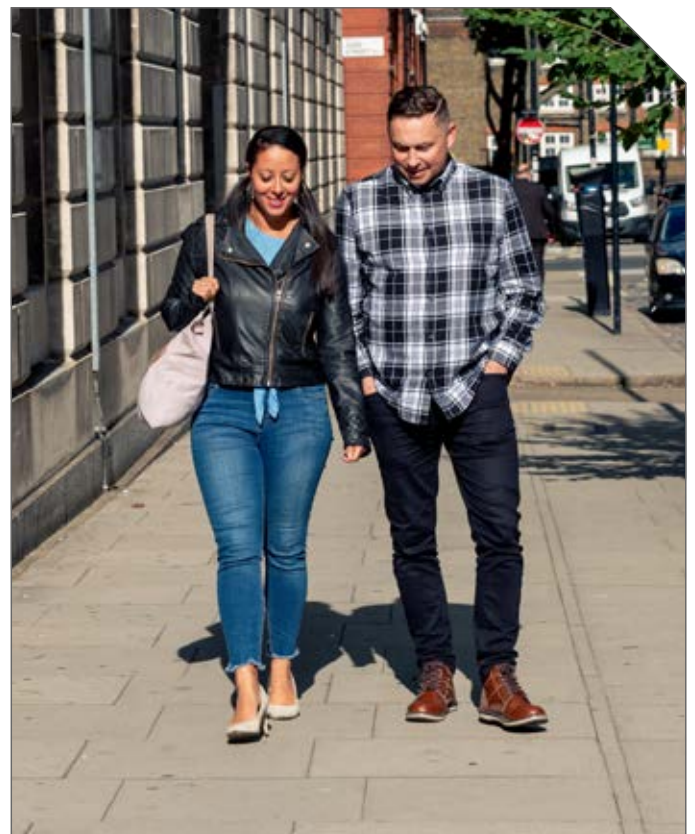
People generally have the confidence to ask friends and family for support but are less comfortable asking for help from neighbours or more formal agencies such as social workers, charities or religious groups.

There is a high level of independence with domestic tasks, with around 75 per cent claiming they rarely need help with personal care, getting dressed or getting around the home. However, two in five claim they always or frequently need help with DIY and a quarter need support cleaning.

Having V I can put pressure on personal relationships and cause the dynamic to change as blind and partially sighted people tend to feel guilty because of their growing dependency and not wanting to be a burden. As a result, they are more likely to struggle through tasks rather than express their needs to their families.

“I try not to discuss my issues with my family, I keep it to a minimum. I don't want it to affect them. I'd rather just suffer alone.”

“My husband tends to take on all of the stress and anxiety of what I'm going through – I don't talk to him as much about it. I don't know any other way now. I've lived with this for 11 years.”





A strong supportive network can play an important role in helping people to come to terms with their V I, but family and friends seldom get any support themselves as they take on caring responsibilities.

**“If your sight problems have escalated quickly, other members of your family might need support and help coping, for example, the children might need counselling. I’ve noticed my children are quieter. It’s not just about the V I person but their family too as they could be struggling a lot – more in some cases.”**

Blind and partially sighted parents also worry about not being able to fulfil their role as a parent and provide the sense of stability expected from their child. Their growing dependency on partners for

tasks such as checking their children’s homework makes them feel ‘useless’. Overall, blind and partially sighted people worry about the impact their V I has on their families and wonder if they need support to cope with it.

Younger parents with V I who are also well adapted are motivated to create a more inclusive world which influences their parenting style. They often teach their children about the privilege that accompanies being sighted and how they should be accepting of all people.

As the ability to participate in their passions and hobbies reduces, some blind and partially sighted people feel they are losing their friends and their networks are shrinking. In addition, people who are still learning to accept their V I tend to enjoy social interactions less and less. They struggle being out at night, find it hard to differentiate between faces in busy rooms and struggle to make sense of group conversations.



**“ I’ve lost friends because I had to give up golf. It’s a social activity. I used to play in a bit of a group, but I’m now only in contact with one person. Golf was the only real connection for the friendship and now that’s gone.”**

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**“ I’m 30 now and my friends have kids so we don’t see each other as much and I might not see them for weeks so I’m spending a lot of time alone. I just go out alone to get out of the house. It would be nice to meet more people. I am more interested in meeting people my age with sight loss.”**

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Some well adapted people are likely to seek out connections with blind and partially sighted people by engaging

with V I organisations through volunteering and fundraising. For some, this connection is a means to finding support, while for others it is a source of friendship.

## **Sector considerations**

**As a sector, we must think about the following:**

- How can the sector target relatives of blind and partially sighted people – for example, the adult children of older people – to offer them information, guidance and support in navigating their loved one’s diagnosis and supporting them to regain their independence?
- How can the sector provide better signposting and access to services aimed at carers, including emotional support and respite care?
- How can the sector facilitate connections between people caring for someone with V I so they can share experiences and offer each other peer support?







## 5.9 Engagement with V I charities and support services

RNIB is by far the most contacted charity (30 per cent), followed by Guide Dogs (16 per cent) and local charities (12 per cent). More than half said they have never contacted a charity. A person is significantly more likely to have contacted a charity if they have a severe V I.

Despite RNIB's size, Guide Dogs is felt to have a more prominent and well-known voice, and they expect RNIB to be doing more to raise public awareness and provide more tailored information about their condition.

The perception that some V I charities only cater for those who are completely blind is a significant barrier to reaching out for support, even if their V I is severe.

**“ I haven't accessed the support groups as I'm not sure they're really for me. I'd love to get a guide dog but I don't think my sight loss is severe enough.”**

A poor diagnostic experience reduces the likelihood of seeking support later. Often people don't feel support is 'designed for them'; they either feel support isn't right for them because of their age or they assume they're 'not blind enough'.



Earlier in stages of adaption, people don't identify with V I organisations and struggle to differentiate between them. When they do opt into a specific service, they don't explore the wider eco-system of support that's on offer. People at this stage are less likely to be supporting the V I community by fundraising, campaigning or volunteering as they are very early on in their own V I journey.

Many remain dissatisfied with the support they've received – they either haven't looked or found what they are looking for, or have received confusing or disappointing support. Often, people received support that was then withdrawn, have had a bad experience with a staff member, or haven't been contacted about a query – and they don't have the confidence or persistence to follow up.



**“ I’ve been very disappointed with the organisations. I’ve had to reconnect with them to get aids, but the guy in charge hasn’t called me back despite me chasing several times.”**

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Interactions with V I charities are varied depending on personal experience, levels of acceptance and the desire to engage with the V I community. There’s very little sense of commitment to supporting these charities simply because they have V I. People are more motivated to engage with the V I community to pursue specific activities, interests and sports.

People who are well adapted wish the comms from several V I organisations were more accurate and reflected the



degrees of vision impairment, alongside the different levels of adaptation. Some are more open to supporting V I charities, as even if they haven’t needed their services, they know they are there. They are also more likely to get involved in volunteering or fundraising activities for V I charities to show their support and connect with other blind and partially sighted people through challenge fundraising events. However, others are more likely to have a transactional relationship with V I charities to get grants or information about technology.

**“ I offer technical assistance to The Macular Society as a volunteer, helping get people set up on things like Alexa and Amazon Fire.”**

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**“ With RNIB, the first thing I think about is campaigning. I don’t tend to use them for support because I have more localised charities near me. They are campaigning to make national changes – not just for my specific condition, but for blind and partially sighted people in general. I tend to use Retina UK for condition-specific things. I tend to see RNIB more as a campaigning national voice.”**

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**“ I did reach out to The Macular Society, but that was more to link up with people for charity walks as I love to walk. We have a WhatsApp group and we do give each other help and advice around sight loss, but walking is the main topic.”**

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## **Sector considerations**

**As a sector, we must think about the following:**

- How can the sector be a positive and authentic voice and representation of people with V I, putting lived experience at its heart and influencing society to be more inclusive?
- How could the sector build relevance and increase reach by improving communications around the breadth of sight conditions supported by charities?
- How can we make sure these communications outline what blind and partially sighted people need, when they should seek or expect support, and how to access it – and make it clear that relevant support is available for them?
- How can we offer this support from diagnosis to empower people to navigate the support pathway more independently in the future?
- How can the sector take a more directive approach in seeking blind and partially sighted people out and communicating with them at existing touchpoints in their journey – particularly through existing, trusted channels such as health and social care professionals?
- How can the sector engage with and equip other organisations and bodies, including health and social care providers and other third sector organisations such as Age UK, to offer support and signpost to relevant services?
- How can the sector highlight and signpost mainstream products and services that meet the accessibility needs of blind and partially sighted people and embody best practice?
- How can the sector encourage adapted and interested blind and partially sighted people to be part of the conversation and show that we are interested in the value they can bring? How can we offer them specific volunteering and employment opportunities that benefit from their lived experience, such as role modelling and mentoring activities?
- How can the sector empower blind and partially sighted people with the tools to make a difference in their own spheres, such as guidance or training about how to communicate about V I and campaign for their needs?
- How can the sector bring about greater representation of blind and partially sighted people in public and civic life by encouraging them to get involved and celebrating their achievements?

# 6. Report conclusions



We produced this report to provide much needed insight into the experiences of people living with V I. Through hundreds of in-depth conversations, we have an improved understanding of how the experiences of blind and partially sighted people are shaped by their mindset and other circumstances.

This mindset is often resilient, proactive and forward thinking. It's clear from this research that people with V I are not passive and have no wish to be perceived this way. A common theme we found is their resilience and proactivity – their determination to seek out and explore ways of thinking, working and living that help them to adapt to living with V I as independently as possible.

Despite this, it's clear that people with V I continue to experience barriers and obstacles due to circumstances beyond their control and that these have a real and direct impact on their mindset and how they adapt and adjust.

We all have a responsibility to understand the aspirations and anxieties of people living with V I.

It is our hope that by highlighting the different experiences of sight loss, this report will encourage people and organisations to think creatively about how they meet the individual needs of people living with V I. Through the delivery of inclusive products, services and policies, blind and partially sighted people can lead independent and fulfilling lives.



# 7. Appendix

## 7.1 The age profile of our sample

The table below outlines the age profile of the vision impaired population and our sample (table has three columns and five rows – the first column shows the total V I population, the second shows the unweighted profile of the sample, and the third shows the weighted profile of the sample):

Profile of total V I population	Profile of our sample – Unweighted	Profile of our sample – Weighted
1 per cent aged 0-17	3 per cent aged 13-17	2 per cent aged 13-17
20 per cent aged 18-64	59 per cent aged 18-64	48 per cent aged 18-64
20 per cent aged 65-74	17 per cent aged 65-74	25 per cent aged 65-74
59 per cent aged 75+	21 per cent aged 75+	25 per cent aged 75+

Interviews were conducted over the phone as the most inclusive and cost-effective methodology. However, we still faced barriers to reaching people in the top age group for a mass survey and did over-represent people aged under 75 years old. We used the customer lists from RNIB and Guide Dogs to target the oldest group and boost the number of interviews. A fifth of the unweighted sample were 75 or over and we weighted to 25 per cent to make sure that the older part of the population had a voice within our sample.

While the over 75s are underrepresented compared to the overall blind and partially sighted population, many people in this age band are simply impossible to reach no matter the methodology:

- They may not recognise themselves as having a vision impairment.
- They may live in an environment where they cannot be reached (e.g. care home).
- They may have other conditions which means talking to them is difficult (e.g. dementia, Alzheimer's, etc.).

## 7.2 The V I profile of our sample

We have weighted our sample in terms of the severity of their vision impairment – 50 per cent have mild vision impairment (22 per cent unweighted), 31 per cent have moderate vision impairment (29 per cent unweighted) and 19 per cent have severe vision impairment (49 per cent unweighted). This is in line with the vision impaired population excluding people with uncorrected refractive errors.

Vision impairment severity has been defined using accepted methods in the charity and government sectors including vision impairment registration status and functional questions (ability to see ordinary footprint, see people across a room and see people or things in the periphery of vision).

## 7.3 The nations

We spoke to people with a V I in all of the devolved nations. In the table below, you can compare the population size for the four devolved nations in the UK and our sample (table has two columns and five rows – the first column shows the profile of the UK devolved nations population, and the second column shows the profile of the sample achieved):

UK Nat Rep Population	Profile of our sample (unweighted)
England 84 per cent	England 70 per cent
Scotland 8 per cent	Scotland 11 per cent
Wales 5 per cent	Wales 9 per cent
Northern Ireland 3 per cent	Northern Ireland 9 per cent



## 7.4 Other facts about our sample

Over half (54 per cent) of the sample have lived with vision impairment for five years or more and 8 per cent since birth. On average, our participants have lived with vision impairment for 21 years. 10 per cent of those we spoke to were BAME.

We covered a wide range of vision impairments with Cataract, AMD and Glaucoma showing as the most frequent. The table below has one column and 20 rows – it outlines the percentage of people with different V I in our sample:

Table:
Cataract (age related) 18 per cent
Glaucoma 15 per cent
Dry AMD 13 per cent
Wet AMD 10 per cent
MD/dystrophy (not age related) 8 per cent
Diabetic Eye condition 8 per cent
Optic nerve condition 8 per cent
An injury or an accident 7 per cent
V I due to a stroke, brain tumour or brain damage 6 per cent
Keratoconus or corneal dystrophy 5 per cent
Cataract (congenital) 5 per cent
Nystagmus 5 per cent
Detached retina 4 per cent
Retinitis pigmentosa 4 per cent
Retinal disease (inherited) 3 per cent
AMD (Unknown) 3 per cent
Uveitis 2 per cent
Cortical visual impairment 1 per cent
Retinopathy of prematurity 1 per cent
Any other condition(s) 25 per cent



**R N I B**

See differently



RNIB registered charity in England and Wales (226227), Scotland (SC039316), Isle of Man (1226). Also operating in Northern Ireland.

Guide Dogs for the Blind Association registered charity in England and Wales (209617) and Scotland (SCO38979)

Thomas Pocklington Trust registered charity (1113729)