# My Voice 2015

The views and experiences of blind and partially sighted people in the UK

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## Foreword

For blind and partially sighted people to live the independent lives they choose to, we as individuals and organisations working alongside them must always remain grounded in the everyday experiences of people with sight loss.

My Voice 2015 serves as an important reminder of the views and experiences of registered blind and partially sighted people in the UK today. Throughout the report, over 1,200 voices are heard - telling us clearly about how life is for them, and how certain services and support could make a difference. The design and findings of My Voice build on ‘Seeing it My Way’, the outcomes blind and partially sighted people have told us they want to achieve in their lives.

I am especially thankful to all the people who have been involved in coproducing this report. We have involved blind and partially sighted people at all stages, from the initial design of the research through to thinking about the key messages from the results and presenting the findings.

My Voice provides a strong evidence base to support our collaboration through the UK Vision Strategy to work more innovatively than ever before. In 2015, it is simply unacceptable that people with sight loss cannot walk safely down the street or read basic information about their medication. It is particularly shocking that so many people who want to work are still unable to find it, and that a worrying number of people who could benefit from emotional and practical support do not receive it when they need it most.

My Voice brings us a clear message directly from blind and partially sighted people that they are missing out on crucial services and support. We must use these findings to look critically at our work and strengthen our efforts to make every day better for everyone affected by sight loss.

Lesley-Anne Alexander CBE

Chief Executive

RNIB

## Acknowledgements

We would like to thank the many people who have supported this project. In particular we would like to thank the blind and partially sighted participants who gave their time to talk about their experiences. The research was made possible by the support of 22 local authorities who helped us at the participant recruitment stage of the project. We also thank the Social Care Institute for Excellence for their guidance and support in securing the multiple ethics agreements required for the project, and thank the Association of Directors of Adult Social Services for their endorsement.

Special thanks go to NatCen Social Research for their dedication in delivering the fieldwork to a high standard. In particular, we would like to thank: Valdeep Gill, Stephen Sharman, Sally McManus, Chris Lord, Pablo Cabrera-Alvarez and all the interviewers at the Telephone Unit who did such a good job in guiding our survey participants through the questionnaire.

Many individuals have given time and energy to help make My Voice 2015 possible. In no particular order, we would like to thank: Dr Kate Flynn, Graeme Douglas, Gray Robinson, Jim Leeder, Annette Dinnall, Philippa Simkiss, Jayne Graham, Shaun Leamon, Judith Howson, Fazilet Hadi, Devia Gurjar, Yolanda Christian, Hugh Huddy, Mark Langdon, Pat Mossop, Sara Preibsch, Steve Tyler, Sue Keil and all the RNIB members who gave us feedback on the design of the questionnaire and materials.

My Voice is a project wholly supported by RNIB and there are no financial interests to declare.

## 1. Headline findings

This summary provides headline findings from the My Voice 2015 research. These key themes have emerged from interviews with over 1,200 registered blind and partially sighted people speaking about their circumstances and experiences.

#### There was huge variation in the experiences and views of blind and partially sighted people

While it is possible to talk about the barriers and restrictions faced by blind and partially sighted people as a whole, there were huge variations in people’s circumstances. Some factors were particularly influential, such as age, amount of functional vision, the age at which someone experienced sight loss, and whether or not someone had additional disabilities.

#### Residual sight was unstable, and people experience changes in sight over a long period of time

For many people, their residual sight was unstable. They experienced changes in functional vision over many years, and this may mean that they need to learn and relearn how to adapt to living with sight loss. Nearly half of people now registered blind were initially registered as partially sighted, and nearly three-quarters of blind and partially sighted people have experienced deterioration in their sight over the last 12 months. For most people, sight loss was not a linear journey along a fixed pathway, but rather a series of changes and challenges that they needed to adapt to.

#### Feelings of wellbeing were lower among blind and partially sighted people when compared to the rest of the population

People with sight loss felt less optimistic about the future, felt less useful and felt less close to other people when compared to the general population.

#### The majority of people did not receive any emotional support in relation to their sight loss

Only 17 per cent of people experiencing sight loss were offered emotional support in relation to their deteriorating vision. This was linked to age, with younger people far more likely to have been offered support to help them come to terms with sight loss. However, many people wanted this type of support, as two-thirds of people of working age and one-third of people of pension age said they would have wanted emotional support if it were available to them.

**Some people wait many years for their sight loss to be registered**

Four in every ten blind and partially sighted people had to wait more than three years to be registered as blind or partially sighted after experiencing sight loss for the first time. This was not limited to people with less severe sight loss as one-quarter of people who were registered blind waited more than five years to be registered.

#### Only a small proportion received key elements of practical support

The support most commonly received by people experiencing sight loss was in relation to gadgets and aids and advice on benefits. Less than one in three received any mobility training in the first year after experiencing sight loss, and only one in five received practical support around the home with things like preparing food. This was linked to age, with older people far less likely to receive support with mobility or with preparing food than younger people.

#### Most blind and partially sighted people relied on some form of care, and often this was informal and unpaid

The majority of blind and partially sighted people needed some form of help around the house. This support ranged from tasks like preparing meals or personal care to help with setting heating controls or help with picking out the right clothing. Nearly half of blind and partially sighted people said that they always or frequently needed support to read written information. This support was provided both from within and outside the home. In the home, support was typically provided by the spouse or partner and, depending on the age of the person, either children or parents. People from outside the home who provided care were typically paid support workers, friends or neighbours, children or siblings.

#### The proportion of people in employment has decreased

Only 22 per cent of blind and partially sighted people of working age were in paid employment, and a further four per cent said they were self-employed. This compares to 28 per cent in paid employment and five per cent in self-employment in 2005 (Douglas et al, 2006). There was a connection between level of vision and employment status, people with poorer functional vision were much less likely to be in employment.

#### Blind and partially sighted people of working age were struggling financially

One in five blind and partially sighted people said they have some or great difficulty in making ends meet. This was linked to age and more pronounced for those of working age, with almost half of   
30–49 year olds and just over one third of 50–64 year olds struggling financially. Nearly half of people of working age cannot afford to pay for a week’s holiday away from home, or a necessary but unexpected expense of £500. More than one-quarter of blind and partially sighted people of all ages said that the disability benefits they received were rarely or never enough to meet the extra costs incurred as a result of their sight loss.

#### Travel and transport remains a major issue for blind and partially sighted people, especially obstacles on the pavement

Four out of every 10 blind and partially sighted people were not able to make all the journeys that they wanted or needed to make, and around half required support to get out of the house. Two-thirds of people of working age and one-third of people of pension age had collided with an obstacle on the pavement in the last three months. One in every three incidents led to the person involved being injured. The most common types of obstacles identified by people were street furniture, parked cars, advertising boards and wheelie bins.

#### Blind and partially sighted people feel cut off from the people and things around them

Four out every 10 blind and partially sighted people felt moderately or completely cut off from people and things around them. This was of particular concern for those over 75 years of age, with over half of this group living alone.

#### Many blind and partially sighted people have limited choice about they spend their free time

Half of blind and partially sighted people said that they were always or frequently limited in the activities that they were able to take part in. One in four people reported that they had little or no choice about how they spent their free time. In addition, nearly two-thirds said that they would like to do more physical activity.

#### Access to key information was an ongoing problem

Nine out of ten blind and partially sighted people said that information on medication or food packaging was quite difficult or impossible to read. In terms of information sent from services, 40 per cent said that information from health providers was never accessible and 28 per cent said that information from banks was never accessible.

#### There was a generational divide in the use of technology

One in three blind and partially sighted people felt able to make the most of new technology. However this was closely linked to age: 86 per cent of 18–29 year olds said that they could make the most of new technology, compared to 25 per cent of people aged 75 and over. There was a significant generational divide in the use of computers, the internet and smartphones, with a particularly low level of technology usage among people aged 75 years and over. The majority of people who do not currently use technology would like to use it if obstacles were removed.

#### Public awareness and attitudes towards sight loss was poor

Over one-third of blind and partially sighted people said that they sometimes, frequently or always experienced negative attitudes from the general public in relation to their sight loss. Younger people and people who were registered blind were more likely to report negative attitudes from the general public. Nearly half of blind and partially sighted people of working age said they had been treated unfairly by others in the last 12 months due to their sight loss, with strangers on the street and retail staff being the most commonly reported sources of unfair treatment.

#### Sight loss was the biggest barrier that people face

When people were asked to talk about the reasons why they experienced difficulty or restrictions, whether in relation to travel, employment, technology, or leisure, by far the most common reason given was their sight loss. It is clear that many people, including those with a range of other challenges and impairments, considered sight loss as the major factor in stopping them from doing all the things they would like to do in life.

## 2. Introduction

This is the first report from RNIB’s My Voice project. My Voice 2015 investigates the views and experiences of registered blind and partially sighted people. The findings are based on interviews with over 1,200 participants from all parts of the UK. My Voice 2015 was funded and delivered by RNIB. NatCen Social Research conducted the telephone interviews between November 2014 and April 2015.

### 2.1 Aim and objectives

The aim of the My Voice project is to better understand the circumstances, views and experiences of registered blind and partially sighted people over time.

To achieve this aim we have the following objectives:

* To establish a random sample of registered blind and partially sighted people.
* To ensure that this sample achieved a good distribution across age groups and areas of the UK, and that it was generalisable to the wider group of registered blind and partially sighted people.
* To conduct telephone interviews with this sample of blind and partially sighted people.
* To keep in touch with participants over the next few years and beyond, to help us understand how their views, opinions and experiences change over time.

### 2.2 Existing research

There are a number of studies focused on blind and partially sighted people and the general population that helped to inform this research. In 1991, RNIB conducted a comprehensive survey of blind and partially sighted people. This produced information about the circumstances, needs and restrictions for blind and partially sighted people in the UK (Bruce, McKennell and Walker, 1991).

In 2006, the Network 1000 project surveyed around 1,000 registered blind and partially sighted adults in Britain. This research conducted by the University of Birmingham in partnership with Vision 2020 UK, provided robust and generalisable data in relation to the registered population (Douglas, Corcoran and Pavey, 2006). A second wave of Network 1000 interviews was conducted in 2008 on the topic areas of finance and benefits, employment, and access to services.

Another report entitled “Functionality and the Needs of Blind and Partially Sighted Adults in the UK”, was produced by Guide Dogs in 2006 (Pey, Nzegwu and Dooley, 2006). This project recruited 1,155 blind and partially sighted people by drawing on existing service users of sight loss organisations across the UK to take part in a survey. Where comparison was possible, the findings in this study were broadly similar to those reported by Network 1000.

Data collected in general population surveys has also been used to highlight the circumstances of people with sight loss. These government funded surveys involve a wide range of participants and are not limited to people with sight loss. “Circumstances of people with sight loss” (McManus and Lord, 2012), and “Living with sight loss: updating the national picture” (Flynn and Lord, 2015) both use data from the Life Opportunities Survey and Understanding Society. This type of secondary analysis is particular helpful because we can compare the circumstances of blind and partially sighted people to those with other disabilities and the general population.

### 2.3 The need for My Voice

Since the last large-scale survey of registered blind and partially sighted people, Network 1000 in 2005, there have been substantial changes in UK society. Causes include the global recession in 2009, the increased use of computers, mobile phones, internet and social media, welfare reform and cut backs in services like adult social care provision. Secondary analysis of administrative and general population survey data suggests that blind and partially sighted people may have been affected more by these changes than other disabled people, and those without any impairment (Byron, Blake and Bridges, 2013; Flynn and Lord, 2015).

Therefore, we needed to update the evidence on the views and experiences of blind and partially sighted people. This updated evidence can then be used for strategy planning, policy and service design, fundraising, influencing and prioritising future research.

## 3. Methodology

This section provides an overview of the methodology of the research, including how participants were recruited, weightings and some of the limitations of the My Voice 2015 study.

### 3.1 Research design

#### Overview of research design

This research report is based on data collected from over 1,200 registered blind and partially sighted people in the UK. These participants were recruited in two different ways. Firstly, we worked with 22 different local authorities to send information to registered blind and partially sighted people. We contacted around 300 people in each location, with the registered population in each area stratified by five different age bands, and then selected at random.

Secondly, we contacted people who were existing RNIB customers and known to be blind or partially sighted. We decided to contact people using this method because it provided a cost effective way of increasing our sample size, and because we were unable to gain access to registered blind and partially sighted people in Northern Ireland by any other means.

Each person who gave their consent to participate in the research took part in a telephone interview between November 2014 and April 2015. The interviews took an average of 45 minutes to complete, and were conducted by NatCen Social Research.

#### Registered blind and partially sighted people

Certification and registration are two separate but linked processes. A Certification of Vision Impairment (CVI) is usually completed by a consultant ophthalmologist, who determines eligibility for certification depending on visual acuity, visual fields and other factors. This completed certificate is then forwarded to the relevant social services department, who should then offer registration to each individual. Local authorities are required to maintain a register of blind and partially sighted people (Boyce, 2012).

There are around 340,000 registered blind and partially sighted adults in the UK. The exact numbers are hard to establish because information on the register is not published in Northern Ireland, and it has not been updated in Scotland since 2010. In addition, the age banding used in the published reports varies between England, Wales and Scotland (HSCIC, 2014; Scottish Government, 2010; Welsh Government, 2014).

#### Groups who were not represented or under-represented in this survey

Blind and partially sighted children and young people under the age of 18 were not in scope of the My Voice project. There is a range of other research that highlights the experiences of children and young people, both in terms of education and also wider issues such as confidence and social inclusion. Further information can be found via RNIB’s Knowledge Hub at [www.rnib.org.uk/research](http://www.rnib.org.uk/research).

As this project focuses on registered blind and partially sighted adults who were able to take part in a telephone interview, there were some key groups that were under-represented, or were not represented at all. These included:

* Older people living in residential care.
* People from minority ethnic groups who do not speak English.
* Adults with sight loss and complex needs.
* People who are deaf blind.
* People with sight loss who were not registered blind or partially sighted.

It is important that the voices of these people are also heard. There will be a companion report “My Voice: case studies”, which will provide a summary of some in-depth interviews with participants who may not have otherwise been able to take part in the research. This report will be available in 2017 from [www.rnib.org.uk/myvoice](http://www.rnib.org.uk/myvoice).

#### Ethics

An ethics application was made to the Social Care Institute of Excellence, which approved the research design. In England, the project was also endorsed by the Association of Directors of Adult Social Services research committee. We also submitted ethics applications to a number of local authority research sites in response to requirement for local ethics clearance.

### 3.2 Description of the My Voice sample

The 1,223 registered blind and partially sighted people who took part in My Voice were recruited via the registers of blind and partially sighted people held by 22 social services departments. These areas were chosen at random, using a statistical selection model, in England (16 councils), Scotland (three councils) and Wales (three councils). In order to ensure the sample contained sufficient participants to enable production of country level findings in addition to this UK level report, we also utilised existing RNIB contact lists to approach blind and partially sighted people about taking part in the research, and this included people in Northern Ireland.

All findings in this report relate to participants who were registered blind or partially sighted. We did speak to 84 participants who were not registered, with the majority of this group from Northern Ireland. These participants who were not registered have been excluded from the data analysis used in this report as we wanted to focus on the experiences of people who are registered.

In terms of the age profile of the sample:

* 10 per cent were aged 18–29,
* 27 per cent were aged 30–49,
* 22 per cent were aged 50–64,
* 21 per cent were aged 65–74,
* 20 per cent were aged 75 and over.

Other key demographic variables among the My Voice 2015 sample were:

* Ethnicity: 89 per cent were White British, and 11 per cent were from all other ethnic groups.
* Gender: 47 per cent were men, and 53 per cent were women.
* Registration status: 59 per cent were registered blind. 40 per cent were registered partially sighted and one per cent did not know their registration status.
* Geographical location: 44 per cent lived in England. 28 per cent lived in Scotland. 21 per cent lived in Wales and seven per cent lived in Northern Ireland.

In terms of the sampling, 57 per cent of participants were recruited via RNIB contacts and 43 per cent from local authority registers.

#### Weighting

In order to achieve one of the My Voice objectives - to highlight the views and experiences of the registered blind and partially sighted population in different age groups, we deliberately set out to recruit equal numbers from five different age groups: 18–29, 30–49, 50–64, 65–74 and 75 years and over. As only around one in ten registered blind and partially sighted people are under the age of 50, we applied a design weighting to secure sufficient respondents from younger age groups to enable us to present findings for people of working age.

A second My Voice objective was to ensure findings were generalisable to the wider population of registered blind and partially sighted people. So we designed a response weighting scheme to take into account the differences between the wider population of registered blind and partially sighted people, and the people who took part in the research.

The weighting scheme resulted in a single number that takes into account the age distribution of all registered blind and partially sighted people. It has been applied to the My Voice dataset, matching the serial number of the respondent to the weight for that respondent (each respondent has a unique weight within the overall weighting scheme). Thus the findings described in the My Voice 2015 report can be generalised to the UK registered blind and partially sighted population.

#### Bias

In all research there is a response bias. For the My Voice research some people were more likely to volunteer to take part in a 45 minute telephone interview than others. There were also groups of people who were excluded or less likely to take part, for example, people who were blind or partially sighted who were not registered, or those who could not take part in a telephone interview. We did not talk to people with complex needs, or people with hidden sight loss living in care homes, or those from ethnic groups who were unable to speak English. Additional bias in the My Voice sample may have been introduced because some participants were recruited from existing RNIB contacts.

### 3.3 Structure of this report

To include even basic tables in this report would add several dozen pages to an already lengthy document, and therefore we have decided not to do this. Instead, we have published an interactive tool that allows the creation of a range of custom cross-tabulations. This tool enables users to view tables linked to sections of this report and to investigate areas of interest in more detail. It can be downloaded from [www.rnib.org.uk/myvoice](http://www.rnib.org.uk/myvoice).

All percentages used in this report have been rounded to the nearest whole number. This means that in some cases when added together the percentages add up to more than 100 per cent.

Some of the results apply only to a specific sub-group of participants. Examples include the employment section, which relates only to people of working age, or the question about whether someone had difficulty in accessing social services, which was posed only to people who used the service in the last 12 months. In all of these cases, we have stated which sub-group of participants the given percentages apply to.

We refer to “working age” and “pension age” in this report: the definition of working age used in this report is male participants aged 18–64 and female participants aged 18–62 years. The state pension age for women is currently undergoing a phased increase, and by 2018 the pension age for both men and women will be 66 years (HM Government, 2015).

Finally, we use the term “age standardisation”. This is important when comparing the circumstances of blind and partially sighted people to the general population because the age profile of these groups is so different, with blind and partially sighted people being older. Age standardisation gives these groups the same age profile so that we can be sure that any differences were due to sight loss and not as a result of older age.

## 4. Findings

### 4.1 Relationships and household

This section highlights the relationship and housing situation of blind and partially sighted people including marital status, the type of accommodation, who was living there and how they were related.

#### Relationships

Marital status was closely linked to age. While none of the participants aged 18–29 were widowed, 43 per cent of those aged 75 and over were. Younger people were much more likely to report their marital status as single, 79 per cent of 18–29 and 46 per cent of 30–49 year olds said that they were single. People in the 18–29 age group were more likely to be living with someone as a couple (12 per cent). People aged 50–64 (51 per cent) and 65–74 years (65 per cent) were more likely to be married. Finally, people aged 50–64 were more likely to be divorced (18 per cent).

Half of people of pension age lived alone, compared with one-third of people of working age. This evidence suggests that blind and partially sighted people, particularly those of working age, are more likely to be living alone than the general population. In England and Wales, around 10 per cent of people in the general population aged 50 and under were living alone in 2011 (ONS, 2014). This compares to 19 per cent of blind and partially sighted people aged 18–29 and 30 per cent of people aged 30–49 years.

For participants who were living with other people, those aged 30 years and over were more likely to be living with their spouse or partner. Those aged 18–29 were more likely to be living with their parents. In terms of living with children, 15 per cent of those of working age were living with children under the age of 16 years.

#### Household

The majority (61 per cent) of blind and partially sighted people owned their home, though this was closely linked to age. Only 30 per cent of people of working age owned their home outright, compared to 71 per cent of people of pension age. Younger people were much more likely to have been renting their accommodation, with 43 per cent of people of working age renting from a landlord. For the youngest participants, 38 per cent of 18–29 year olds lived in their home rent free, for example, with family. Overall, 25 per cent of people rented accommodation from landlords, with housing associations, local authorities or private landlords the most common.

### 4.2 Sight conditions and sight loss

This section highlights the level of sight loss among participants, when it occurred, the eye condition or conditions that caused it, how sight had changed over the last 12 months and participants’ self-reported level of functional vision.

#### Sight loss

"[They] could have diagnosed it sooner and more accurately. Every time I went it was something different. It took them 20 years to diagnose correctly."

People were asked when they or someone else first noticed that they had a sight problem that was affecting everyday life. Overall, 28 per cent of participants were either born as blind or partially sighted or experienced sight loss as children, 32 per cent had experienced the onset of sight loss during working age, and 40 per cent experienced the onset of sight loss in older age. In more detail, 41 per cent of people aged 18–29 had been blind or partially sighted from under the age of two years, compared to five per cent of people of pension age. In terms of people of pension age, 27 per cent had experienced sight loss between the ages of 65–74, and 26 per cent had experienced sight loss over the age of 75 years.

This was similar to the profile of Network 1000 participants. In that study, 18 per cent of participants experienced sight loss between 0–16 years, 33 per cent from 17–64 years and 49 per cent from 65 years and over (Douglas et al, 2006). However, this is lower than we would expect to find in the general population of blind and partially sighted people, with around three-quarters of Certifications of Vision Impairment being issued to people over the age of 65 years (RNIB, 2014).

Those who experienced sight loss as adults were asked about who first noticed that they had a problem with sight that was affecting their everyday life. The majority said that they first noticed problems with their vision themselves (59 per cent). Optometrists or opticians identified problems in 28 per cent of people. It was notable that other hospital departments or services (such as a diabetes nurse or stroke ward) first noticed sight problems in seven per cent of participants of working age.

We also asked participants to estimate how long they had been registered blind or partially sighted. Fourteen per cent of people had been registered for one year or less, and 17 per cent had been registered for between two and three years. Around one-fifth of people had been registered for more than 20 years. Of those aged 75 and over, more than one in three (37 per cent) were registered three years ago or less.

#### Eye conditions

"[The] eye clinic were not sure what was happening. They felt my sight was going to come back, but it didn't."

Overall, macular degeneration was the leading cause of sight loss among all participants (48 per cent). It was particularly common among older participants, with two-thirds of people aged 75 years and over having AMD. The second most common cause of sight loss was glaucoma (16 per cent), and the third most common eye condition was cataract (12 per cent). Other commonly reported eye conditions were Retinitis Pigmentosa (10 per cent), and diabetic eye disease (eight per cent). A wide range of other eye conditions were also linked to sight loss. This was particularly evident for those of working age with over half of this group identifying other eye conditions as the cause of their sight loss.

In terms of the number of eye conditions people identified, the majority (78 per cent) were living with one eye condition. A further 18 per cent were living with two eye conditions, with five per cent living with three or four eye conditions.

#### Changes over time and current care

"[The] eye clinic should have given more support of what is going to happen to you as the condition gets worse over time, after you have been diagnosed."

While many people had been living with an eye condition for many years, they continued to experience changes in their vision over time. For example, of people now registered as blind, 47 per cent were at one stage registered as partially sighted.

When asked about how their vision had changed over the last 12 months, 71 per cent of people said that it had deteriorated. This was closely linked to age, with 81 per cent of people aged 75 and over reporting that their sight had got worse, compared with 33 per cent of those aged 18–29. Only three per cent of people said that their sight had improved in the last 12 months.

The majority of blind and partially sighted people were still regularly visiting the eye clinic. Nearly half of people had their most recent appointment within the last six months, and a further 18 per cent within the last year. Only 17 per cent had not had an appointment within the last two years. Participants who had been registered for over 20 years were much more likely not to have been to an eye clinic for the last five years (32 per cent), despite the fact that over half (53 per cent) of this group reported that their sight had deteriorated in the last 12 months.

This evidence highlights that losing sight is not a one-off event. These findings from the My Voice 2015 survey are reinforced by Network 1000, in that study 56 per cent of blind and partially sighted people said that the difficulty they had with their sight was greater than a year ago (Douglas et al, 2006).

#### Functional vision

Participants were also asked a series of questions about their functional vision. These questions were originally used in the “Blind and partially sighted adults in Britain” report (Bruce, McKennell and Walker, 1991) and then repeated in Network 1000 (Douglas, Corcoran and Pavey, 2006).

As we would expect, the self reported levels of sight were closely linked to registration status. Partially sighted people were far more likely to be able to recognise a friend across a room or the road than someone who was registered blind (31 per cent, compared with 10 per cent).

Poor functional vision was linked to age, 30 per cent of participants of working age either had no light perception or could not make out the shapes of furniture in a room, compared to 14 per cent of people of pension age.

Overall, seven per cent of people had no light perception, while 10 per cent could tell by the light where windows were, but could not see the shapes of furniture in a room. Nineteen per cent of people had enough vision to make out the shapes of furniture in a room, but could not see well enough to recognise a friend’s face. A further 23 per cent could recognise a friend if they were close to their face, and 20 per cent could recognise a friend at arm’s length. Finally, 14 per cent of participants could recognise a friend across a room, and a further seven per cent could recognise a friend across a road.

### 4.3 Early support

This section explores the early support that was offered to people in the initial stages after experiencing sight loss and during the process of registering as blind or partially sighted. The focus is on elements of emotional and practical support, both in the eye clinic and support provided by the local council. The majority of the questions were asked only to participants who had experienced sight loss as an adult. However all participants were asked if they had ever been offered any specialist support in the eye clinic and how satisfied they were with the information and advice they had been given in the eye clinic over the years.

#### Support in the eye clinic

“It would have been nice to have some support at all. The consultant that first diagnosed me didn't have any bedside manner.”

“I can’t think of anything else that they could have done. They were quite helpful.”

All participants were asked whether or not they had ever been offered any specialist support at the eye clinic, for example from an Eye Clinic Liaison Officer or a Vision Support Service. In total, 38 per cent of participants had been offered this type of support at some stage, but 62 per cent have never been offered any support. There was no link to age. People who had been registered for one year or less or four to eight years reported highest access to support in the eye clinic: 44 per cent and 47 per cent had been offered support compared to 23 per cent of people who had been registered for more than 20 years. Those registered as partially sighted had been offered more support than those registered blind.

All participants were also asked about their overall level of satisfaction with the information and advice they had received in the eye clinic over the years. Two-thirds of people were either completely or quite satisfied with the information and advice they received, while 21 per cent were not very or not at all satisfied. This means that within the whole population of registered blind and partially sighted people around 70,000 people were not happy with the information and advice they have received at the eye clinic over the years.

#### Emotional support

“I needed someone there to talk through the diagnosis. I had to go home and Google it. It was very clinical and doesn't take into account the shock and your feelings.”

Seventeen per cent of blind and partially sighted people who experienced sight loss as adults had been offered counselling or emotional support to help them come to terms with their sight loss. This was linked to age: 57 per cent aged 18–29 reported that they had been offered emotional support and this proportion decreased with each age band, down to 15 per cent of people aged 75 or over.

In terms of timing, 17 per cent of people who had been offered emotional support were first offered it at the time of diagnosis, and 26 per cent received it between diagnosis and registration. A further 40 per cent were offered emotional support either at the time of registration or within a year of registration. Finally, 17 per cent had to wait more than a year after they were registered in order to receive emotional support.

We asked those who were not offered any emotional support whether or not they thought that they would have wanted to access this type of service. Overall, 33 per cent said they would have wanted some emotional support. This was linked to age: 62 per cent of people of working age wanted emotional support, compared to 29 per cent of those of pension age.

#### Practical support

“[They] could have come out and showed me things, like how to use kettle without being scalded.”

“I had lots of falls and could have needed the help, but I didn’t get any help and hurt myself a lot.”

Participants who experienced sight loss as adults were asked about the length of time from experiencing sight loss to being registered as blind or partially sighted. In total, 28 per cent of people were registered within a year of experiencing sight loss, and a further 29 per cent were registered within three years. However, 14 per cent were registered between three and five years after experiencing sight loss, and 29 per cent had to wait more than five years to be registered. Unfortunately, we do not know when these people would have been eligible for certification and registration.

We also asked about how long people had to wait after their initial contact with social services to receive a visit from them. The largest group of participants (42 per cent) received a visit within six weeks. Nine per cent had to wait more than six months and seven per cent more than a year for a visit from social services. One in five people reported that they had never received a visit. Waiting a long period of time for a visit from social services was not limited to participants with less severe sight loss, nine per cent of people who were registered blind had to wait more than a year for a visit, and 19 per cent never received one.

We also asked people who experienced sight loss as adults about any practical support they had received in relation to their sight loss in the first 12 months. The most common forms of support received were advice about aids and gadgets (69 per cent) and advice on benefits (46 per cent).

In total, 30 per cent of people received mobility training in the first 12 months after experiencing sight loss. This was linked to age, with more than half of people aged under 50 years having received mobility training. In contrast, only 26 per cent of people aged 75 and over received mobility training. People who were registered blind were more likely to have received mobility training (37 per cent) compared to people who were partially sighted (24 per cent).

In terms of practical support in the home: 33 per cent of participants were given advice on lighting, 22 per cent were given support with moving around the house and 20 per cent were given support with preparing food or cooking. Support with food preparation and moving around the home was linked to age. For example, 45 per cent of people aged 18–29 were given support to move around the home, compared to 20 per cent of people aged 75 and over. One in five blind and partially sighted people said that they had received no practical support in the first year after experiencing sight loss.

We also asked people who had some light perception if they had ever been offered a low vision assessment (LVA). These appointments can help identify the need for a magnifier, monocular or other visual aids. Overall, 72 per cent of people had been offered a low vision assessment. There appears to be no link between age or level of sight loss in the likelihood of being offered access to LVA services.

Finally, we asked participants about how satisfied they were with the practical support they had received in the first 12 months after experiencing sight loss. Over half (56 per cent) said that they were completely or quite satisfied, whereas 11 per cent said that they were not very or not at all satisfied.

#### Support for families and carers

“It would be helpful for my family to have basic training and help, and some guidance.”

We also asked people who had experienced sight loss as adults about how satisfied they were with the amount of support available to their families. Overall, 39 per cent were completely or quite satisfied, but one-quarter were either not very or not at all satisfied with the information and advice available to their families whilst they were experiencing sight loss. Finally, 17 per cent said that they did not have any family.

### 4.4 Health and wellbeing

This section highlights wider health issues that blind and partially sighted people face, including difficulties caused by other disabilities. It also provides some information about overall wellbeing, based on responses to questions from the Short Warwick-Edinburgh Mental Wellbeing Scale.

**General health**

Over half (52 per cent) of blind and partially sighted people said that their general health was either very good or good. This was linked to age, 67 per cent of 18–29 year olds said that they were in good health, compared to 51 per cent of people aged 75 years and over. In contrast, 16 per cent of people said their health was bad or very bad.

All participants were asked about any other long term physical health conditions. Older blind and partially sighted people were the most likely to report other health conditions. In total, 51 per cent of people aged 18–29 and 37 per cent of people aged 30–49 reported no other health problems, compared to 16 per cent of people aged 65 and over. Overall, 40 per cent of blind and partially sighted people reported one other health condition, while 24 per cent had two health conditions, and 16 per cent had three of more health conditions.

The most common additional health problems experienced by participants were: high blood pressure (28 per cent), arthritis (26 per cent), diabetes (19 per cent), heart conditions (19 per cent), spinal or muscular pain (10 per cent) and asthma or allergies (9 per cent). As we would expect, some of these additional health conditions, such as arthritis, heart disease and high blood pressure, were linked to age.

**Ability to carry out a range of tasks**

We asked participants a number of questions about whether or not they had any difficulties with a range of tasks, such as hearing, mobility or dexterity, in addition to being blind or partially sighted. Around one-quarter (26 per cent) reported that they had no additional difficulties. Overall, 29 per cent of people said they were limited in one other area of life, 24 per cent were limited in two additional areas, and 21 per cent were limited in three or more areas.

The most common additional difficulties were related to mobility (44 per cent), hearing (35 per cent), dexterity (29 per cent), memory (16 per cent) and mental health (15 per cent). Many of these additional difficulties were linked to the age of the participant. Older people were more likely to have difficulties with mobility or hearing. Younger people were more likely to have no additional difficulties or mental health problems.

#### Wellbeing

The Warwick-Edinburgh Mental Wellbeing Scale was developed for assessing positive mental health. The short version is a scale consisting of seven positively worded questions, and it covers most aspects of positive mental health, including positive thoughts and feelings (Warwick University, 2015). All wellbeing questions ask people to state how they have been feeling over the last couple of weeks.

In terms of the wellbeing of blind and partially sighted people, around one-third (30 percent) felt optimistic about the future often or all of the time. However a proportion of blind and partially sighted people had a less positive outlook:

* 31 per cent of people were rarely or never optimistic about the future.
* 26 per cent rarely or never felt useful.
* 19 per cent rarely or never felt relaxed.
* 12 per cent of people felt that they rarely or never dealt with problems well.
* Four per cent of people said that they were rarely or never able think clearly.
* 13 per cent of people said that they rarely or never felt close to other people.
* Three per cent of people said that they were rarely or never able to make up their own mind about things.

Some of the wellbeing questions were linked to age. Older participants were less optimistic about the future, but were more likely to report feeling close to other people and feeling relaxed.

When compared to the general population, blind and partially sighted people have lower wellbeing in several areas. People with sight loss felt less optimistic about the future, felt less useful and felt less close to other people when compared to the general population. For example, one in four blind and partially sighted people rarely or never felt useful, compared to one in 10 people in the general population (McManus and Lord, 2012).

### 4.5 Domestic life

This section explores the domestic life of blind and partially sighted people. This includes any care that was provided to them and who was providing it to them. This section also includes information on participants who were providing care to other people.

#### Support around the home

“[I would like] someone to help around the house that isn't my husband, to take the pressure off him.”

“[I would like] carers on board so I would feel less of a burden to my parents.”

In total, 48 per cent of blind and partially sighted people said that they needed help around the home. This was linked to age; more people of working age reported that they needed support (63 per cent, compared to 43 per cent of people of pension age). Needing support around the house was also linked to overall level of functional vision; participants with a greater degree of functional vision reported needing less support around the home. For example, around one-third of people who could see a friend across the road said they needed help around the house compared to around two-thirds of people who could not see the shapes of furniture in a room. Additional disabilities were also a factor, with people who identified being limited in three or more areas of life being twice as likely to need support around the home than those with no additional disabilities (72 per cent compared to 36 per cent).

We asked a series of follow up questions to participants who had identified that they needed support around the home. We asked about how frequently they needed help with specific tasks.

* 68 per cent always or frequently needed support with cleaning.
* 61 per cent always or frequently needed support to prepare meals.
* 28 per cent always or frequently needed support with personal care, such as washing or dressing.
* 16 per cent always or frequently needed support getting around the home.

Support was provided both by people within and outside the household. For people who lived with someone else, the vast majority (89 per cent) received support from someone in the household. This was most likely to be provided by a spouse or partner (78 per cent) or a son or daughter (21 per cent). For younger people this support was also likely to be provided by their parents.

In addition, 59 per cent of people received support from someone outside of their household. The most common form of outside support was from a paid support worker (39 per cent), a son or daughter (29 per cent) or friends or neighbours (25 per cent). Blind and partially sighted people of working age also received support from their parents or siblings (both 20 per cent).

We also asked participants whether the amount of the support they received, either from people in or outside the home, was enough to help them in their daily lives. Nearly one-quarter of blind and partially sighted people said that the support was only sometimes enough, and 14 per cent said that it was rarely or never enough.

Finally, we asked those who did not identify that they needed extra support around the house a follow-up question about any help they needed with day to day activities, such as setting heating controls, identifying items of clothing or reading instructions on food or medicine. Of this group of participants, 48 per cent said they did need help with day to day tasks around the home.

#### Caring for others

“I need more help, as I care for my mum and I’m losing my sight.”

We also asked whether participants provided care for someone else who had a long-term health condition, disability or age-related ill-health. Fifteen per cent of blind and partially sighted people were carers. This was linked to age and it was more common for blind and partially sighted people aged 30–49 (21 per cent) and 50–64 years (24 per cent) to be carers.

Among carers, it was most likely that they provided care for a spouse or partner (48 per cent). Support was also being provided for relatives in a different household (24 per cent), relatives in the same household (14 per cent) or someone else (17 per cent). This varied by age, with older participants much more likely to care for their spouse or partner, and participants under the age of 50 years being more likely to care for a relative living in the same household.

Blind and partially sighted carers provided a wide range of help and support:

* 96 per cent kept an eye out for someone or helped by being available if needed.
* 93 per cent were providing social support.
* 60 per cent were providing support with preparing meals, cleaning or other household tasks.
* 59 per cent were providing support to get to the shops or the GP.
* 30 per cent were collecting or giving medications.
* 29 per cent were assisting with paperwork or collecting benefits.
* 23 per cent were helping people get up or down the stairs or in or out of bed.
* 17 per cent were helping with personal care.

The support provided was linked to age. People of working age were more likely to provide support with trips to the shops, with paperwork, with collecting benefits and helping with personal care.

Over one-third (36 per cent) of people providing care were doing so for more than 20 hours each week. A further 30 per cent were providing care for less than four hours each week.

Finally, we asked carers about how satisfied they were with the support they received as a carer. Nearly half (46 per cent) said that they did not receive any support, and a further 11 per cent of carers said that they were either quite or very dissatisfied with the support they received.

### 4.6 Learning and work

This section focuses on access to learning and employment opportunities for blind and partially sighted adults. This includes some information about whether participants were engaged as full or part time students, employment status and the support provided to those in work or looking for work.

#### Employment status

“My main issue for the last few years was the lack of my job. It affected everything, I couldn't plan my future, had to move back in with parents. Affected me socially. But now I’ve got my life back on track.”

Focusing on participants of working age, 22 per cent were in paid employment and four per cent were self-employed. A further 22 per cent described themselves as unemployed, 25 per cent as long term sick or disabled, 16 per cent said that they were retired, four per cent were looking after family or home, three per cent were students and four per cent were doing something else.

The Network 1000 study of registered blind and partially sighted people, which was conducted in 2005, found that 28 per cent of participants were in paid employment and five per cent were self-employed. Therefore, there has been a significant decrease in the proportion of registered blind and partially sighted people of working age in any form of employment over the last decade from 33 per cent in 2005 to 26 per cent in 2015.

By way of comparison with the general population, in April 2015, 73 per cent of the UK general population were in employment (DWP, 2015). In addition, six per cent of the UK population were unemployed and 22 per cent were said to be economically inactive. Please note that these official employment rates start from 16 years of age and apply a strict definition to the term “unemployed”. An unemployed individual must have sought work in the last four weeks. My Voice 2015 participants were 18 years and above and reported their employment status from their own subjective perspective.

Within the My Voice working age population, employment status varied at different life stages. Those aged 30–49 were the most likely to be in paid or self employment (35 per cent). Those aged 18–29 were much more likely to describe themselves as students (21 per cent), or as unemployed (30 per cent). People aged 50–64 were more likely to report that they had retired from work (30 per cent).

There was a connection between paid employment and functional vision, with only around one in 10 people with poor functional vision in paid employment, that is, no light perception or not being able to see the shapes of furniture in a room. This compares to 39 per cent of people who could see well enough to recognise a friend across the road in paid work.

The impact of additional impairments on employment status was even more evident. We asked participants whether they had any other impairments that caused difficulties in any other areas of life, for example, with mobility, hearing or mental health. In total, 37 per cent of people who reported no other impairments, that is, sight loss only, were in paid employment. This compared to 21 per cent who reported one additional impairment, 14 per cent who reported two additional impairments and six per cent of people who reported three or more additional impairments.

#### People in employment

“I did work in computers for a long time in my life. When my condition was diagnosed it was then realised that sitting in front of my computer was having a detrimental effect on my health. My employer took two years to make adjustments.”

“There seems to be a...lack of knowledge on the support you get and the duties of employer to provide this.”

Of the 22 per cent of blind and partially sighted people of working age who were in paid employment, the majority were in full time employment (63 per cent) and 89 per cent had permanent jobs. In terms of different types of employer, 38 per cent were employed in the private sector, 49 per cent in the public sector and 13 per cent in the voluntary sector.

Half of working age people in paid or self-employment had received help through the government’s Access to Work scheme. Participants identified a range of support that had been put in place by their employer, either with or without support from Access to Work. In total, 48 per cent had been provided with special aids or equipment, 32 per cent said their employers had identified adaptations to the working environment, 29 per cent had been allowed time off work and 33 per cent had been given flexibility in working hours. However, one in four people in employment said that their employer had made no adjustments.

We asked people to comment on their overall satisfaction with support they received and although the majority (65 per cent) were very or quite satisfied with what was being provided to them, 9 per cent were either quite or very dissatisfied with the support in place.

#### Work Capability Assessment

The Department for Work and Pensions use a test called the Work Capability Assessment (WCA) to determine eligibility for Employment Support Allowance. There are three possible outcomes from this assessment based on capacity to work.

Among participants of working age, 35 per cent had received a WCA. Of this group of people, 67 per cent were allocated to the Support Group, in other words these people were found “not fit for work”. There was a link between likelihood of being found not fit for work and the number of additional impairments. Half of people with no additional impairments who had a WCA were allocated to the Support Group, compared to four out of five people with two or more additional impairments.

In addition, 22 per cent were allocated to the Work Related Activity Group and 11 per cent were found Fit for Work. Overall, 23 per cent appealed their WCA decision, with four out of five people in this group being satisfied with the result of this appeal.

#### People who were unemployed

“Being blind has already put limitations on employment. Also unable to drive a car puts even more limitations for employment.”

“I had never have been out of work. Then having to go to the job centre due to unemployment, I have received no help.”

Only 26 per cent of those who said that they were unemployed were actually looking for a job at the time of the interviews. This varied with age, with 38 per cent of 18–29 year olds looking for work, compared to 20 per cent of those aged 50–64 years.

Among the group of unemployed people who were not looking for paid employment, only half said that they wanted to find a job. So even though a high proportion of blind and partially sighted said they were unemployed compared to the general population (23 per cent compared to six per cent), a much smaller percentage were actually seeking or wanted to find a job.

Of the unemployed people who wanted to work, over one-quarter were not receiving any support to find a job. In addition, one-third of people looking for work were dissatisfied with the support they had received.

Unemployed participants were also asked how likely they felt it was that they would find employment in the next 12 months. Over three-quarters said that they thought this was unlikely or very unlikely. The most common barrier to employment identified by this group was sight loss (64 per cent). Other common factors were problems caused by a long term health condition or other disability (28 per cent), lack of suitable jobs (25 per cent), attitudes of employers (17 per cent) and a lack of support (15 per cent).

#### Learning

#### Education status

As we would expect, the likelihood of currently being a student was heavily linked to age. Among the 18–29 year age group, 21 per cent were in full time and seven per cent were in part time education. Only three per cent of people aged 30–49 years were in full time education, and four per cent were studying part-time. In addition, five per cent of people aged 50–64 years said that they were studying part time.

The vast majority of students were either enrolled in a university or a Further Education college course.

#### Highest qualification

Participants were asked a series of questions about different types of qualifications. In total, 27 per cent had a degree or higher level qualification, while 33 per cent were identified as having no qualifications. Older participants were more likely to have no qualifications than younger people, and 38 per cent of people of pension age reported having no qualifications compared to nine per cent of people aged under 50 years.

#### Access to learning opportunities

One in five blind and partially sighted people said that they did not have access to all the learning opportunities they would like, while 31 per cent said that they were not interested in learning new things. The feeling of being restricted in learning was not linked to age, but not being interested in learning new things was. Older participants were much more likely to say that they were not interested in learning new things compared to younger people.

We asked participants who felt restricted in learning opportunities about the reasons why. The most commonly reported reasons were issues relating to sight loss (51 per cent). Other barriers were lack of support or options from training providers (23 per cent), availability or accessibility of equipment (21 per cent) and problems with travel (20 per cent).

### 4.7 Finances and benefits

This section highlights the financial situation of blind and partially sighted people. It contains information about how people were coping financially, overall household income, the benefits people were receiving, and whether this income was enough to cover the extra costs related to disability.

#### Making ends meet

“Money gives you choices. When you don’t have it you can’t make the choices.”

“More financial security would be a big step to be able to get out and about the way that you want to, and to purchase any big items for the home that sometimes need replacing.”

Nineteen per cent of blind and partially sighted people reported having some or great difficulty in usually making ends meet. This was closely linked with age: 46 per cent of 30–49 year olds and 36 per cent of 50–64 year olds had difficulty in making ends meet, compared to only 11 per cent of people aged 75 and over.

The most common reasons given for not being able to make ends meet were limited income (70 per cent) and the increased cost of living (68 per cent). Forty per cent of people who identified issues with making ends meet reported that the extra costs related to sight loss was one of the main reasons for them having difficulty managing financially.

People of working age considered themselves to be much worse off financially than older people. This may be related to the fact that only 26 per cent of this group were in employment.

* 46 per cent of people of working age could not afford to pay for a week’s holiday away from home, compared to 18 per cent of people of pension age.
* 46 per cent of working age people could not afford to pay for an unexpected but necessary expense of £500, compared to 21 per cent of people of pension age.
* 15 per cent of people of working age could not afford to keep their house adequately warm, compared to six per cent of people of pension age.

Finally, we asked participants about whether the disability benefits they received helped to meet the extra costs associated with sight loss. Nineteen per cent of blind and partially sighted people said that their disability benefits were only sometimes enough, and a further 28 per cent said that these benefits were rarely or never enough to meet the extra costs related to sight loss.

#### DLA and PIP

“The main support I could have done with help with is benefits. [I was waiting to receive anything for six months].”

“[I want] to have no worries and be informed about DLA benefit. I am worried about the future, what support I'd get in the future.”

Disability Living Allowance (DLA) is a benefit paid to disabled people to help them meet the extra costs associated with their disability. It is awarded to people under the state pension age, but claimants can be above pension age if they were awarded DLA prior to claiming their pension. DLA is paid in two components (mobility and care), and each component has a different level of award depending on the extent of a claimants needs. From April 2013, the Personal Independence Payment (PIP) started to replace DLA, with all new claims being for PIP instead of DLA.

The vast majority (88 per cent) of people of working age were in receipt of DLA, and a further 42 per cent of people of pension age. Focusing on participants of working age, registration status was a factor in claiming DLA, 94 per cent of people who were registered blind were claiming DLA compared to 77 per cent of those registered as partially sighted. People who had been living with sight loss for longer were also more likely to be claiming DLA, with 98 per cent of people of working age who have been registered for more than 20 years getting the benefit, compared to 47 per cent of people who had been registered for one year or less. This will be as a result of the change to PIP for people that have experienced sight loss since 2013, when the benefit replaced DLA for new claimants.

We also asked participants who were claiming DLA about the rate of the benefit they were receiving. In terms of the care component, 26 per cent were in receipt of the highest rate, 38 per cent the middle rate, 30 per cent the lower rate and seven per cent did not receive this component. The rate received was linked to registration status. Just over half of people of working age who were registered blind were in receipt of the middle rate, whilst just over half of these registered partially sighted were in receipt of the lower rate.

In terms of the mobility component, 42 per cent of DLA recipients were in receipt of the higher level, 47 per cent received the lower level and 11 per cent did not receive this component. People of working age who were registered blind were more likely to have been in receipt of the higher rate (68 per cent), while people registered partially sighted were more likely to have been in receipt of the lower rate (68 per cent).

Fifteen per cent of people of working age had been assessed for PIP. The majority of these (76 per cent) had been awarded PIP as a result of this assessment. Of this group, 52 per cent said that the amount they were awarded under PIP was higher than what they were receiving under DLA.

#### Attendance Allowance

Attendance Allowance is a benefit paid to people over the age of 65 to help with personal care because of a disability. An individual cannot claim both Attendance Allowance and Disability Living Allowance. Among older people, 27 per cent of people aged 65–74 years and 59 per cent of people aged 75 and over were claiming Attendance Allowance. Over half of these claimants (56 per cent) were awarded the higher rate of the benefit.

People who were registered blind were more likely to be in receipt of Attendance Allowance than those registered partially sighted (69 per cent compared to 51 per cent). The number of additional impairments was also a factor, 41 per cent per of people with no additional impairments were in receipt of Attendance Allowance, compared to around two-thirds of people with two or more additional impairments.

#### Income

We asked participants a number of questions about their personal income. We asked them to think about their income from all sources before deductions for tax. My Voice findings represent participants' perception of their own personal income, and do not necessarily reflect the overall income of the household.

Personal income was closely linked to age, 15 per cent of people of working age reported an income of under £99 per week compared to 4 per cent of those of pension age. Low income was a particular issue for younger people with 26 per cent of 18–29 year olds earning under £99 a week. In total, 60 per cent of blind and partially sighted people reported a personal income below £300 per week, with 22 per cent between £100 and £199 and 31 per cent between £200 and £299. A further 16 per cent reported their weekly personal income as between £300 and £399.

In comparison to the general population, 58 per cent of people in Great Britain have a personal income below £300 each week (McManus and Lord, 2012). After standardising for age, the proportion of blind and partially sighted people with a personal income under £300 each week was 68 per cent. These personal income figures do not show the extra costs incurred by blind and partially sighted people as a result of their disability. So while the evidence suggests that people with sight loss have lower incomes compared to the general population, they also have higher expenditure (Hill et al, 2015).

### 4.8 Transport

“I suppose transport is the main one. If I was here on my own it would be very difficult to afford a taxi very often. At the moment my husband takes me to the hospital.”

This section highlights issues related to travel. It includes how often blind and partially sighted people leave the house, whether or not they require support to do so and what mobility aids they use. It also includes information on access to bus and train travel, and difficulties with obstacles on pavements.

#### Getting out and about

“[I would like] more freedom to get out and about, to do different things for myself.”

“Driving gives you independence. If you want to go out somewhere or just go home, if you can’t drive then you can’t do that, you rely on other people.”

Forty per cent of blind and partially sighted people were unable to make all the journeys that they wanted or needed to make. Furthermore, 22 per cent of people were only sometimes able, and 23 per cent were rarely or never able to get out and about how and when they chose. This was linked to level of functional vision. Around one-third of people with poor functional vision were rarely or never able to get out how and when they chose. This compared to seven per cent of people who could see well enough to recognise a friend across a road.

All those who were not able to make all the journeys they wanted to were asked an additional question about the factors that stopped them from travelling. Nearly two-thirds (61 per cent) identified problems related to sight loss as a barrier to travel. Other common issues were the lack of availability or accessibility of public transport (35 per cent), issues related to mobility (28 per cent), lack of confidence (27 per cent), issues related to other health conditions or disabilities (23 per cent), not being able to go out alone (22 per cent) and difficulty in getting to public transport (22 per cent).

In terms of getting out of the house, nearly half of blind and partially sighted people left their home every day, with an additional 37 per cent leaving their home at least a couple of times a week. Those with additional impairments left the home less frequently, 26 per cent of people with three or more additional impairments left home once a week or less compared to five per cent of people who had no additional disabilities.

Over half of blind and partially sighted people said that they needed support to get out of the house. Level of functional vision was a key factor in needing support, 73 per cent of people with poor functional vision needed help to get out and about compared to 31 per cent of people who were able to recognise a friend across a road.

The support provided to blind and partially sighted people in relation to travel was primarily provided by family, friends and neighbours. This was linked to age, with older people, up to the age of 75, more likely to receive help from a spouse or partner, and younger people more likely to receive help from other family members.

Nearly three-quarters (71 per cent) of blind and partially sighted people used a mobility aid. The type of mobility aids that people used was often linked to age:

* 45 per cent of people of working age used a long cane, compared to 18 per cent of people of pension age.
* 17 per cent of people of working age used a symbol cane, compared to 19 per cent of people of pension age.
* Seven per cent of people of working age used a walking stick, compared to 29 per cent of people of pension age.
* 14 per cent of people of working age used a guide dog, compared to five per cent of people of pension age.

#### Bus and train travel

“Teach bus drivers to park near the kerb so that you don't fall when getting on and off the bus. People tend to push you while getting on the bus and that can be scary.”

“I would love to see the train station or airport to have lower signs as they are too high to read.”

Three in ten blind and partially sighted people were not able to travel by bus as much as they wanted to. The most common barriers related to bus travel were issues related to sight loss (49 per cent), difficulties in seeing bus stops or identifying the right bus (32 per cent), issues associated with walking to the bus stop (22 per cent) and problems caused by other health conditions or disabilities (20 per cent).

One-quarter of blind and partially sighted people were not able to travel by train as much as they would like. The most common barriers to train travel were issues related to sight loss (41 per cent), lack of help or support (22 per cent), problems caused by other health conditions or disabilities (20 per cent) and difficulties in seeing trains, platforms or stops (20 per cent).

#### Obstacles on the pavement

“The edge of pavements could be painted yellow, and such a small change like this can make a world of difference to people who have my condition.”

“Get some of the clutter off pavements and clean the place up ...doing this will makes it easier for people with wheelchairs and prams to get about too.”

Finally, we asked participants if they had collided with an obstacle on the pavement in the last three months. Two-thirds of working age people and one-third of people of pension age had collided with an obstacle on the pavement. In around one in three incidents this collision caused an injury.

People identified a range of different obstacles on pavements that they had recently collided with while walking. This included street furniture (48 per cent), wheelie bins (35 per cent), parked cars (33 per cent), advertising boards (30 per cent), temporary obstructions such as building works (23 per cent), trees (18 per cent), refuse bags or recycling boxes (18 per cent), bicycles (13 per cent) or something else (29 per cent).

### 4.9 Access to information and services

This section highlights information about accessing key services, such as health and social care services, as well as everyday things like shops. It also contains information about what formats were used to access information, reader support, and how often services provide information in preferred formats.

#### Reading

“I am a very independent lady, and I have been all my life, and having to have other people to read things for me is very frustrating and not always private.”

Participants were asked about what formats they used to access information. The majority of people used large print (58 per cent) and audio with a human voice (70 per cent). Other formats used were audio with a synthetic voice (35 per cent), standard print (21 per cent) and braille (eight per cent).

As we would expect, registration status played a significant factor in the formats people used to access information. People who were registered blind were much more likely to use synthetic speech (45 per cent compared to 25 per cent) and braille (15 per cent compared to one per cent) than those registered partially sighted. People who were registered partially sighted were more likely to use print (29 per cent compared to 13 per cent) and large print (72 per cent compared to 46 per cent).

In terms of needing support to read written information, half of blind and partially sighted people reported that they always or frequently needed support, and a further 24 per cent of people sometimes needed reader support. The requirement for support with written information was linked to functional vision. Around 60 per cent of people with poor functional vision always or frequently needed support with reading. This compared to 20 per cent of people who could recognise a friend across a road.

#### Accessibility of information

“I would like to be more independent. For example when I go to the shops I can't see the sell by date. I have to get my daughter to come with me and I would like to do that myself.”

Forty per cent of people said that information from healthcare providers, such as a GP or hospital, was never accessible, and 18 per cent said this information was only sometimes accessible. In addition, 11 per cent said that they do not deal with any information from health providers themselves and that someone else deals with this on their behalf.

Three out of 10 people said that information from banks was never accessible, and 12 per cent said this information was only sometimes accessible. In addition, 14 per cent of blind and partially sighted people said that they do not deal with any information from banks themselves and that someone else deals with this on their behalf.

A total of 53 per cent of blind and partially sighted people reported that they were able to vote in secret and without support, with a further 24 per cent able to vote in secret but requiring support. One in five blind and partially sighted people said that they were unable to vote in secret. If this proportion is applied to all registered blind and partially sighted adults in the UK, then around 70,000 people with sight loss were unable to vote in secret.

Nearly half (45 per cent) of blind and partially sighted people said they found it impossible to read the instructions on medication. A further 45 per cent said that this was quite or very difficult. This was linked to the level of sight loss: 60 per cent of people registered blind said that it was impossible to read details on medication, compared to 28 per cent of people registered as partially sighted.

Again, nearly half (47 per cent) of blind and partially sighted people said that they found it impossible to read the instructions on food packaging. A further 46 per cent said that this was quite or very difficult. As with medication, this was linked to level of sight loss, 61 per cent of people who were registered blind said reading food packaging was impossible for them.

#### Access to services

We asked participants some questions about accessing health, benefits and social services as these are all important elements of living a healthy and independent life for blind and partially sighted people. We also asked about the amount of difficulty participants had with shopping for everyday necessities.

The vast majority (83 per cent) of blind and partially sighted people had contact with health services, such as the GP or eye clinic in the last 12 months. Of this group of people, 29 per cent had some or a lot of difficulty in accessing these services. Common reasons given for difficulty in accessing health services were problems getting an appointment (51 per cent), problems related to sight loss (30 per cent), difficulty with transport (27 per cent) and unhelpful or inexperienced staff (20 per cent).

Likelihood of contact with a benefits or pensions service was closely linked to age, with 29 per cent of people of working age and six per cent of those of pension age in contact with these service providers. Of this group of people, 45 per cent had some or a lot of difficulty in accessing benefits and pensions services. The most frequent reasons given for difficulty in accessing these services were unhelpful or inexperienced staff (43 per cent), lack of accessible information (36 per cent), issues related to sight loss (24 per cent) and difficulty in contacting the service (23 per cent).

Around a quarter (24 per cent) of blind and partially sighted people had been in contact with social services within the last 12 months. Of this group, 25 per cent had some or a lot of difficulty in accessing these services. The most common reasons given for these difficulties were unhelpful or inexperienced staff (46 per cent), lack of accessible information (23 per cent) and difficulty in getting an appointment (22 per cent).

In terms of shopping, 59 per cent of blind and partially sighted people said that they always or frequently needed help to shop for everyday necessities. While age was not a factor in needing help with shopping, there were significant differences between participants with different levels of functional vision. Around three-quarters of people who could not see the shapes of furniture in a room always or frequently needed help with shopping for everyday things, compared to around one-third of people who could recognise a friend across a street.

### 4.10 Technology

This section provides information about access to technology, including computers, smartphones and the internet. It also highlights people’s feelings about the extent to which technology can help blind and partially sighted people become more independent, and how much people feel that they were able to make the most of new technologies.

#### Attitudes towards technology

“I believe that all blind people should use technology, as it makes you feel more independent as a blind individual. The government should invest more money into teaching people about technology.”

One in three blind and partially sighted people felt able to make the most of new technology. This was linked to age, 86 per cent of people aged 18–29 said that they could make the most of new technologies, this proportion decreased with each age band and only 25 per cent of those aged 75 and over reported that they felt able to make the most of new technology.

Participants who reported that they felt unable to make the most of new technology were asked an additional question about any restrictions they faced. Nearly two-thirds (61 per cent) said the barriers were caused by issues related to their sight loss. Other commonly given reasons were lack of knowledge about using technology (30 per cent) and problems with keeping up to date with what’s new (24 per cent).

We also asked participants whether they felt new technology helped them to become more independent. Again, this was closely linked to age with 79 per cent of those aged 18–29 reporting that technology always or frequently made them more independent, compared to 30 per cent of those aged 75 and over. In addition, 38 per cent of those of pension age reported that technology never helped them become more independent, compared with only 11 per cent of working age participants.

#### Computers

“If I could be able to use the computer it would make my life a little easier.”

Computer usage was linked to age: 79 per cent of 18–29 year olds, 71 per cent of 30–49 year olds, 63 per cent of 50–64 year olds, 52 per cent of 65–74 year olds and 30 per cent of those aged 75 years or over used a computer.

Although computer usage among older blind and partially sighted people remains low, there is some evidence to suggest that it has increased over the last decade. In Network 1000, only 12 per cent of participants of retirement age used a computer. In the My Voice 2015 study, 33 per cent of participants of pension age used a computer.

Blind and partially sighted people who did use a computer did so frequently, with 57 per cent using it every day and a further 20 per cent using it several times a week.

Blind and partially sighted people accessed their computer in a range of different ways, with 82 per cent making some form of adjustment or using access technology:

* 34 per cent used magnification software.
* 32 per cent used screen reader software, but this was linked to age with 45 per cent of working age and 25 per cent of people of pension age using screen readers.
* 41 per cent used a larger screen, made text larger or adjusted the resolution of their computer.
* 11 per cent made some other kind of adjustments.
* 18 per cent did not make any adjustments.

The majority (65 per cent) of people who were not using a computer would like to do so if all obstacles to using one were removed, including 63 per cent of people aged 75 and over. By way of comparison, only 29 per cent of Network 1000 participants who did not use a computer wanted to use one.

Finally, we asked all participants who were not currently using a computer what stopped them from using one. The most common reason given was issues related to sight loss (54 per cent). Other common reasons for not using a computer were not being interested (28 per cent), lack of knowledge about using them (23 per cent) and the cost or availability of equipment (21 per cent).

#### Internet

“[I would like] better access to technology...one problem of being blind is you can’t get information on current events.”

Usage of the internet was heavily linked to age: 98 per cent of 18–29 year olds, 82 per cent of 30–49 year olds, 68 per cent of 50–64 year olds, 54 per cent of 65–74 year olds and 26 per cent of those aged 75 years or over used the internet.

Usage of the internet amongst blind and partially sighted people was lower than that amongst the general population. According to Office for National Statistics (ONS, 2015) data on internet access, 96 per cent of people aged 16–64 in the general population had used the internet, compared to 78 per cent of blind and partially sighted people. The proportion of people of pension age in the general population who had used the internet was 56 per cent, compared to 30 per cent of blind and partially sighted people.

People who used the internet reported using it frequently. Nearly two-thirds said that they accessed it at least once a day. People reported using the internet for a variety of reasons, such as shopping (52 per cent), keeping up to date with local news (51 per cent), travel (42 per cent) and managing money (36 per cent).

The majority of people who were not using the internet would like to: 66 per cent said that if there were no obstacles they would like to go online. This includes 65 per cent of those aged 75 and over, the group with the lowest level of internet usage.

We asked all participants who were not currently using the internet what stopped them from using it. The most common reason given was issues related to sight loss (54 per cent). Other common reasons for not using the internet were not having the skills or the “know how” (30 per cent), not knowing much about it (23 per cent), that it was too difficult (20 per cent) and not having a computer or the right software (18 per cent).

#### Smartphones and tablets

As with computer and internet usage, usage of smartphones and/or tablets was linked to age. Only 16 per cent of those aged 18–29 years did not use a smartphone or tablet. This increased with each age band, with 84 per cent of people aged 75 and over not using such devices.

* 12 per cent of people only used a smartphone, 32 per cent working age, five per cent pension age.
* Nine per cent of people only used a tablet, seven per cent working age, nine per cent pension age.
* Eight per cent of people used both a smartphone and a tablet, 24 per cent of working age, three per cent of pension age.
* 71 per cent of people did not use either, 37 per cent of working age, 82 per cent of pension age.

People, especially those of working age, used their devices for a wide range of activities. The most common uses of these devices were for making phone calls (91 per cent), text messaging (68 per cent), emailing (43 per cent), accessing the internet (39 per cent), listening to music (32 per cent) and accessing social media (30 per cent). People of working age were also likely to use these devices for taking photos (23 per cent), navigation (23 per cent) and games (16 per cent).

If all the obstacles were removed, the majority (61 per cent) of blind and partially sighted people would like to use a smartphone or a tablet, which includes 58 per cent of those aged 75 and over.

Participants who were not using a smartphone or tablet were asked an additional question about any barriers that stopped them from doing so. The most common barrier stated was issues related to sight loss (48 per cent). Other common reasons for not using a smartphone or tablet were not being interested (37 per cent), lack of knowledge (26 per cent) and the cost or availability of equipment (19 per cent).

### 4.11 Discrimination

“[It would make everyday better] to be accepted with a disability. Knowing what’s out there, being understood and being given a chance to get on with my life.”

This section highlights findings related to questions on attitudes towards sight loss, discrimination and hate crimes.

#### Attitudes towards sight loss

“People see you are blind and feel frightened. I wish they wouldn't back away.”

“[I want] to be able to be walk down the street...without being laughed at or pointed at.”

Over one-third (35 per cent) of blind and partially sighted people said that they sometimes, frequently or always experienced negative attitudes from the general public because of their sight loss. This was closely linked to age, with one-quarter of people under the age of 50 years reporting that they frequently or always experience negative attitudes, compared with eight per cent of those aged 75 and over. Level of sight loss also had an impact, with people registered blind (43 per cent) more likely to have experienced negative attitudes than those registered as partially sighted (27 per cent).

We also asked participants whether or not they felt they had been treated unfairly in the last 12 months as result of their sight loss. Responses were linked to age, with 47 per cent of blind and partially sighted people of working age reporting that they had been treated unfairly, compared to 17 per cent of those of pension age. Responses were also linked to registered status, with those registered blind were more likely to report being treated unfairly than those registered partially sighted (30 per cent compared to 19 per cent).

All participants who reported that they had been treated unfairly were asked about their relationship to the people who had treated them in this way. The most common sources of unfair treatment were strangers on the street (63 per cent), retail staff (36 per cent), bus drivers (23 per cent), taxi drivers (14 per cent) and health workers (14 per cent).

#### Hate crimes

“I may be more likely to be attacked if I use the cane because people can see I’m blind.”

A hate crime is a crime that is committed against a person because of their personal characteristics, for example, their religion, ethnic origin, disability or sexual orientation.

We asked participants if they felt they had been a victim of a hate crime in the last 12 months. Again, responses were linked to age: 10 per cent of working age participants reported that they had been the victim of a hate crime, compared with three per cent of those of pension age. Around two-thirds of people who had been the victim of a hate crime said that they thought it was motivated by the fact that they were blind or partially sighted.

### 4.12 Social contact, choice and control

“Feeling confident and empowered to basically achieve and be able to do what I want to do, help people understand my needs rather than just hiding my problems.”

This section summarises information about the amount of social contact that blind and partially sighted people have with friends and family. It also highlights findings in relation to the amount of choice and control people feel that they have over their lives.

#### Social contact

“[I want] more chances to do the same as others... going to the cinema and other leisure things...meeting other teenagers.”

“[I want] more support from people in a similar situation, to have someone of my age who understands what I’m going through.”

Only 2 per cent of blind and partially sighted people said that they did not feel close to anyone, which meant they did not have anyone in their life who they could count on if they had a problem. In total, 23 per cent of people said that they were close to one or two people, 36 per cent said that they were close to between three and five people and 40 per cent said that they were close to more than six people.

We also asked participants about how often they had as much social contact as they wanted. The majority of people (58 per cent) always or frequently had as much social contact as they wanted,

a further 27 per cent of people only sometimes, and 14 per cent rarely or never had as much social contact as they wanted. The feeling of not having enough social contact was linked to the number of additional impairments. Seven per cent of people with no additional impairments rarely or never had enough social contact, compared with 23 per cent of those with three or more additional impairments.

Another measure of social contact is how close people feel to the people and things around them; 40 per cent of blind and partially sighted people felt moderately or completely cut off from the people and things around them.

#### Leisure, physical activity and voluntary work

“I would like to do more walks where there are more people around to talk to.”

“I listen to a lot of talking books. I struggle for something else to fill my day.”

Half of blind and partially sighted people said that they were always or frequently limited in the activities that they would like to take part in. This was linked to a number of factors, with people with more recent sight loss and additional impairments reporting that they were more limited in their leisure choices.

Participants that reported being always or frequently limited in their leisure activities were asked an additional question on the barriers they faced. The most common reason was about issues related to sight loss (78 per cent), with other common barriers being problems related to another health condition or disability (35 per cent), lack of help or assistance (19 per cent) and issues related to public transport (12 per cent).

The majority of blind and partially sighted people (64 per cent) said that they would like to do more physical activity. This was true of people of all ages, 60 per cent of people aged 75 and over said that they would like to do more physical activity. The most commonly reported barriers to physical activity were issues related to sight loss (57 per cent), problems as a result of another health condition or disability (44 per cent), and age (27 per cent).

In terms of volunteering, 39 per cent of blind and partially sighted people said that they were not able to volunteer as much as they wanted to during the last 12 months. A further 29 per cent said that they were not interested in volunteering. This was linked to gender, with 45 per cent of female participants reporting that they were not able to volunteer as much as they wanted, compared to 31 per cent of male participants.

#### Choice and control

“I don’t think enough people are aware of how visually impaired people live their life and what they are capable of.”

We asked participants whether they thought they had the support and skills to make the most of life. The majority of people (79 per cent) said that they did have the support and skills they need. This was linked to additional impairments, 87 per cent of people with no additional impairments reported having the support and skills they need compared with 66 per cent of those with three or more additional impairments.

Around one in four (27 per cent) blind and partially sighted people said that they had little or no choice about how they spend their free time. In contrast, 41 per cent reported that they had a lot of choice.

Participants were also asked about how often they felt free to decide for themselves how to live their life. Over three-quarters (77 per cent) of people said that they were always or frequently free to decide how to live their life. One in 10 blind and partially sighted people said that they rarely or never felt free to decide for themselves how to live their life. People with additional impairments and women were more likely to report that they rarely or never felt free to decide for themselves how to live their life.

## 5. Open response questions

As part of the My Voice 2015 survey we asked participants three open questions to give people an opportunity to talk about whatever they felt to be most important. This section highlights the common themes that emerged, illustrated by direct quotes from blind and partially sighted people.

### 5.1 Early support

Participants who experienced sight loss as adults were asked if, looking back now, they could think of any additional support that could have been provided at the eye clinic or by social services to help them when they first experienced sight loss. In total, 576 people answered this question.

#### Support at the time of onset of sight loss

Positively, the most common response was that people felt that they had been given as much support as they had needed (mentioned by 129 people).

“Not really, I went to RNIB for information. Groups of people came and helped with the information. That was all I needed.”

In contrast, other people highlighted that they received no support at the time of sight loss (mentioned by 45 people). A common thread in the experiences described was that people felt that they were just left to “get on with it”.

“I didn't get any support until a friend intervened. I had no contact from hospital or social services.”

“The specialist was quite abrupt. It was a case of go away and come back when you’re blind.”

#### More information and advice

The most frequently mentioned unmet need around the time that people first experienced sight loss (mentioned by 100 people) was the need for more information, advice and a better explanation of their sight condition. Some people wanted information and advice about the practicalities of living with sight loss, information on what other support was available and how to manage the impact of sight loss on work, transport, benefits and domestic tasks. Some people felt that they needed more medical advice and information when their condition was first diagnosed. In a small number of cases, respondents felt that their sight could have been saved if they received better medical advice.

“A counsellor could have been available to advise on what services and support was on offer at the time.”

“[I wanted] more information about the condition, and potential treatment options.”

“Making me aware of my condition, as I have not received any help to date. I received no treatment from the consultant for two years and my condition just got worse.”

#### Emotional support

Another common response (mentioned by 66 people) was the need for more emotional support at the time of sight loss. People suggested that this emotional support could have come in the form of formal counselling, support groups or simply by having someone to talk to.

“Talking to a trained counsellor would have helped. Or a local drop in centre to be able to go to for advice and to meet other people in the same position.”

“The letter they sent me telling me...it wasn’t even signed I was devastated.”

#### Timely rehabilitation services

A further 30 people highlighted the need for more practical support of the kind typically provided by rehabilitation services. Some people said that they needed help to relearn how to carry out everyday tasks, such as cooking, cleaning and washing, due to their sight loss. Others needed help to relearn how to get around their house safely and avoid falls. Another recurrent issue was the support needed to build confidence to go out of the house to carry out necessary household tasks like shopping.

“They should have trained me how to use the washing machine and how to press the buttons and so on.”

“[I needed] help with getting around the house, I knew the house but it would have helped.”

In total, 21 people commented that the issue was not the support they received, but the time they waited to receive it. They were happy with the support they received eventually, but often had to wait a long time, in some cases years, to get that support.

“I struggled for 12 months without help. It wasn’t necessary; I could have got that help immediately. It would have made a lot of difference.”

“They could have done at the time what they did two and a half years later. After the initial assessment, I was told the lady would be in touch. When I rang the lady was off sick and then left. Eventually, I was re allocated. The support I’ve received since has been excellent.”

#### Other issues

“When I was pregnant I’d have liked more support ...there was no help at all when I returned home, that was very hard.”

“I think someone should have offered support to my son, because it affected him as well due to the fact that I’m a single parent.”

Other types of additional support mentioned by participants included:

* Practical and emotional support for families (mentioned by 14 people)
* Support for parents (of babies or small children) when they first experienced sight loss and needed additional support to be able to cope with family life (mentioned by eight people).

### 5.2 Making everyday life better

We asked participants “What is the one thing that would make everyday life better for you?” Several key themes emerged in their responses: getting out and about, to have more social contact, financial issues, attitude of the general public and availability of practical and emotional support.

#### Travel and mobility

“I would say public transport as they don't come in at the right time or right stop. It's very confusing.”

“To make it easier to get round ... [we need] the reduction of posts, pillars, lampposts and signs. I counted 105 in one street.”

“[I want] the freedom to go out without thinking about whether I may fall over.”

The theme most frequently mentioned was the desire to be able to travel and get out and about more easily (226 people). People talked about the need for better and more accessible public transport and more accessible streets. People highlighted that, as they were unable to drive due to their sight loss, the lack of availability and flexibility of public transport, particularly in rural areas, was a major barrier. People also said that buses and trains need to be more accessible for blind and partially sighted people as they disliked relying on family and friends for lifts and could not afford the expense of taxis. Others commented that they struggled to walk the streets because of pillars, lampposts, signs and cars parked on the pavement.

#### Social inclusion

“I would like to go to places and meet other people because [where I live] there is a programme just once a month for partially sighted people.”

“[I want to] have a new skill that I could offer to the community to feel useful.”

The second most frequently mentioned theme (highlighted by 116 people) was related to social inclusion. People described their desire to be more socially included in different ways. Some wanted more opportunities to take part in sport and exercise so that they could be more socially and physically active. Others wanted the freedom to be able to travel to see friends and family more often. Some people felt very isolated and wanted to be able to meet new people and make new friends. Others specified that they particularly wanted the chance to meet other blind and partially sighted people who understood their experiences. Some wanted to be able to contribute to their community by volunteering and helping others.

#### Finance

“I’ve not been able to afford normal things. There are a lot of gadgets out there but none are free.”

“[I want] more money for transport and taxis for more independence.”

The third most frequently mentioned theme was related to financial issues (mentioned by 83 people). Some people stated that they were in a difficult financial position because they were unable to find work. Others expressed anxiety over the rate of Disabled Living Allowance they received or would receive in the future. Finance was seen as particularly important because of the impact that it has on people’s freedom to make choices and live independently.

#### Practical and emotional support

"[I needed] help with living on my own and basically how to cook and clean or how to arrange domestic help."

“[I would like] to have someone to talk to, to discuss my condition.”

People felt that their everyday life could be improved by professional support to help them to adapt to or cope with their sight loss (mentioned by 77 people). The form of support that people needed varied: some said that they needed emotional support to support them through the transition of their life with sight loss. Others said they needed support with domestic tasks, particularly so that they could feel like “less of a burden” to family members.

#### Public awareness and attitudes

“People have negative attitude towards me because they think I use my benefit to go on holidays.”

“It would be wonderful for people to see me as a person... standing outside school gates I do not get spoken to. When I go swimming I bump into people and they think that I am just rude, and not that I cannot see.”

“Raising public awareness...just because someone does not look vision impaired that doesn't mean that they can see, or they're lying.”

Another common theme (mentioned by 70 people) was the need to improve public awareness of sight loss and to promote a more positive attitude towards blind and partially sighted people. Some gave examples of discrimination they experienced at the hands of the general public. Others described feeling socially excluded and isolated because sighted people behaved inappropriately due to a lack of awareness of sight loss.

#### Other themes

Other themes to emerge were:

* More access to technology, aids and reading materials in accessible formats (63 respondents).
* Securing appropriate employment (46 respondents).
* More accessible public services (20 respondents).

### 5.3 Other important areas of life

We asked all participants, “Are there any areas of life that are important to you that we haven’t covered in the interview?” Around 25 per cent of participants gave some additional comments. Some wanted to discuss topics already covered in the survey in more detail, such as transport, employment and finance. However, there were some additional topics identified by participants.

#### Parenting

“I feel sorry for my daughter and I feel awful that I won’t be able to see her.”

“My children, they were never told about my condition and how to understand it.”

In total, 23 people highlighted the difficulties a person with sight loss has when caring for children or grandchildren. This ranged from discussing the need to help children to understand sight loss to the need for support in the everyday tasks involved in raising children, such as reading, helping with homework and taking them to different places. This was an emotive topic, with some parents and grandparents expressing a sense of guilt about their sight loss.

#### Impact of sight loss on other family members

“How sight loss affects family members...their emotional needs, do they have to adjust their lives to take care of sight impaired person?”

In total, 23 people felt that the survey could have discussed the impact of their sight loss on other members of their family. This group of participants primarily identified that the emotional and practical needs of the rest of their family needed to be met as well as their own.

#### Views and experiences of RNIB

“I would like to have more activities from RNIB for the blind, like attending exercise classes, more activities, even social gatherings.”

“The people like the RNIB are not really there. I feel very isolated living in a very rural area.”

Nineteen people wanted to share their views and experiences of RNIB. Some shared positive experiences of RNIB, while others suggested ways in which RNIB services and products could be improved.

#### Other issues

When we asked survey participants what other issues were important to them, a huge range of individual issues were raised, all of which cannot be discussed within this report. However,

* 16 people talked about religion and faith, with some talking about faith as a source of strength, but others identified inaccessibility of religious services for blind and partially sighted people.
* 13 people highlighted the lack of leisure and holiday opportunities available to blind and partially sighted people.
* 11 people said that would have liked the opportunity to discuss the quality of the health and social care services they had received.
* Eight people talked about their difficulties with romantic relationships and dating in relation to sight loss.

## 6. Next steps

### Other publications from this wave of interviews

This is the first My Voice UK report, and it only offers a small insight into all the data available from the My Voice 2015 survey. One of the best ways to access a wide range of data is to use the interactive tool that has been published alongside this report. This tool gives you access to all the questions asked in the survey. These can be cross-tabulated by a number of other variables: two age bands, five age bands, gender, registration status, age of onset of sight loss, number of years registered, level of functional vision and number of additional impairments.

### Events

We will be hosting a series of regional events in 2016. These will highlight the My Voice 2015 findings and provide an opportunity for people to discuss the consequences of the research in terms of priorities moving forward.

### Case studies report

In early 2017, we will be publishing a report with the voices of some blind and partially sighted people who were unable to take part in the My Voice research. These illustrative case studies will highlight the particular circumstances and difficulties faced by people who have a severe hearing impairment and sight loss, people who do not speak English, and carers of people with people with complex needs.

### Access to My Voice survey data

While we are unable to provide anyone with the raw survey data, we would be happy to run bespoke analysis, and provide custom tables. There is a huge amount of analysis that can be conducted on the My Voice survey data. For example, did receiving mobility training have any impact on participants’ ability to get out and about? Does the use of technology have any impact on people’s wellbeing? If you would like any insights from the My Voice 2015 survey for activities such as strategy development, service planning, fundraising or campaigning, then let us know and will be happy to try and help. Please contact [research@rnib.org.uk](mailto:research@rnib.org.uk) with any requests.

### My Voice wave two interviews

My Voice is a longitudinal study, and almost all participants agreed that RNIB could keep in contact with them for future research. We plan to conduct a second wave of My Voice interviews with the whole sample in 2018. This will give us an opportunity to see how blind and partially sighted people’s experiences change over time, and help us to understand what some of the key drivers for these changes are on daily life.

### Further information

Future My Voice publications can be accessed via [rnib.org.uk/myvoice](file:///\\pbrfp03\InterSiteShare\Users_InterSite\ESI\YChristian\Desktop\rnib.org.uk\myvoice).

If you have any questions, you can contact us by emailing [research@rnib.org.uk](mailto:research@rnib.org.uk).

## Appendix A: References and supporting documents

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## Further information and resources

This document only gives a brief summary of the My Voice project. For more detailed information please go to the full report which can be found at rnib.org.uk/myvoice.

You can also access an interactive tool which you can use to look at the results of the survey in more detail. With this you can build comparison tables to examine differences across a range of variables such as age band, registration status, level of vision and the age sight loss developed.

As this report focuses on registered blind and partially sighted adults who were able to take part in a telephone interview, some groups were not represented. A companion report “My Voice: case studies”, will provide a summary of in-depth interviews with participants who would not have otherwise been able to take part in the research. This report will be available in 2017 from rnib.org.uk/myvoice.

**Knowledge and research hub**

RNIB is a leading source of information on sight loss and the issues affecting blind and partially sighted people.

**Sight loss data tool**

Our Sight loss data tool provides local and regional facts and figures about blind and partially sighted people and those at risk of sight loss.

[www.rnib.org.uk/datatool](http://www.rnib.org.uk/datatool)

**Research reports**

We carry out and commission a widerange of research on the issues that affect blind and partially sighted people.

[www.rnib.org.uk/research](http://www.rnib.org.uk/research)

**Knowledge Exchange Network**

The Knowledge Exchange Network for the Sight Loss Sector has been set up to help professionals generating and using research and information on sight loss. To find out what the network can offer, and to receive our email updates visit: www.rnib.org.uk/ken