



My Voice 2015 Summary

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



Supporting people
with sight loss

Key messages

For many people, losing sight is not a one-off event. People lose sight gradually and experience a number of deteriorations in what they can see. This means that people may need support to learn and relearn how to adapt to sight loss as their sight deteriorates, and this may be a considerable time after certification and registration.

Many people face sight loss without help. Most people do not get any emotional support to help them adjust to losing sight and only a small proportion of people receive the practical support they need.

There has been a fall in employment rates of registered blind and partially sighted people of working age: only one in four were in employment.

Four in every 10 blind and partially sighted people felt cut off from people and things around them. Low income, inaccessible information, difficulties in getting around, and digital exclusion may have contributed to feelings of isolation.

People with the most severe sight loss or those with additional impairments have the worst experience. They are often unable to choose when they go out, need more support with reading and around the home, have limited choice of activities, are much less likely to be in employment and feel less free to decide for themselves how to live their lives.



Four in every 10 blind and partially sighted people felt cut off from people and things around them

We spoke to over

1200

**blind and partially
sighted people from
all parts of the UK**

Introduction

This is a summary of the first report from RNIB's My Voice project. The aim of My Voice is to better understand the circumstances, views and experiences of registered blind and partially sighted people. The last large-scale survey of blind and partially sighted people was carried out in 2005. However, the global recession, welfare reform, cut backs in public services and increased use of technology may have impacted upon the everyday lives of blind and partially sighted people in the last 10 years.

My Voice 2015 provides a much needed update on the realities of life as a blind or partially sighted person in the UK today. My Voice provides a current evidence base to be used for strategy planning, policy, service design, fundraising and influencing across the sight loss sector. Our findings were based on telephone 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.

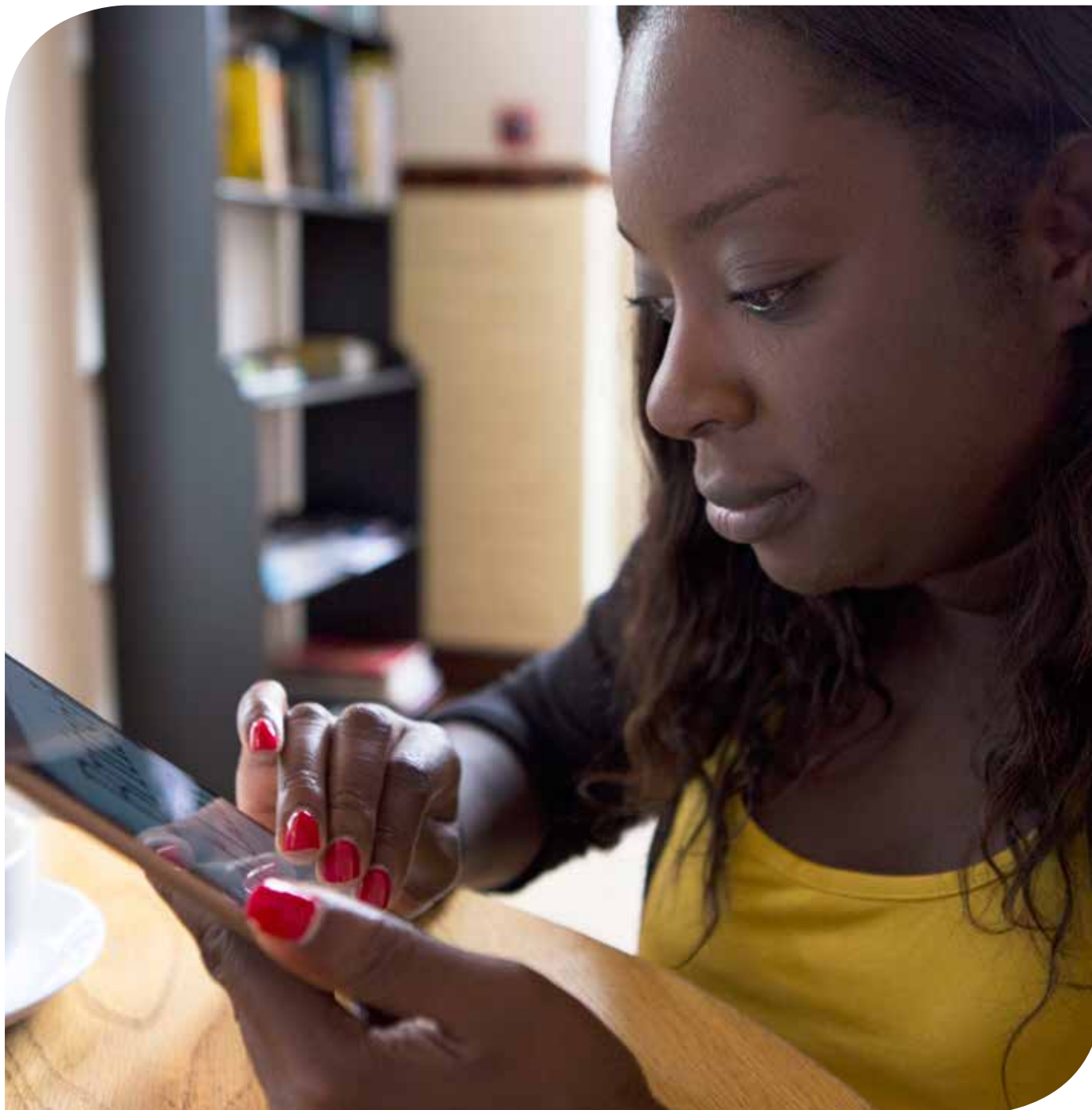


Methodology

Participants were recruited in two different ways. Initially we worked with 22 different local authorities to send information to registered blind and partially sighted people. We also 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.

“The findings presented within this report have been weighted so that they are representative of the general population of registered blind and partially sighted people”

The project was granted ethics approval by both the Social Care Institute of Excellence and the Association of Director’s of Adult Social Services research committee.



1. Headline findings

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

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

Whilst it is possible to talk about the barriers and restrictions faced by blind and partially sighted people as a whole, we must be aware of huge variations in people’s circumstances. Age, amount of functional vision, the age at which someone experienced sight loss and additional disabilities can all have a major influence on someone’s experience.

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

“[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.”

For many people, their residual sight was unstable. Nearly half of people now registered blind were initially registered as partially sighted, and nearly three-quarters of blind and partially sighted people had 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.

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

“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.”



Only 17 per cent of people experiencing sight loss were offered any form of 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 the sight loss. However, many people wanted this type of support. 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.

Feelings of wellbeing were lower amongst 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.

Only a small proportion received key elements of practical support to maintain independence

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

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 preparing food than younger people.



Most blind and partially sighted people rely on some form of help in the home, and often this was informal and unpaid

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

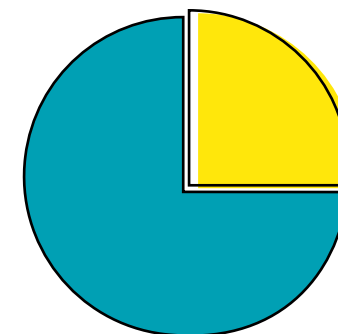
The majority of blind and partially sighted people needed some form of help around the house. This support ranged from tasks like preparing meals or personal care, to help with setting heating controls or help with picking out the right clothing.

Nearly half said that they always or frequently needed support to read written information. This support was provided both from within the home by family, and from outside the home by friends and paid support workers.

The proportion of registered blind and partially sighted people in employment has decreased

“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.”

One in four of blind and partially sighted people of working age were in employment (paid or self-employed). This compares to one in three in employment in 2006.



One in 4 blind and partially sighted people of working age were in employment

There was a connection between level of vision and employment status. Only one in 10 people with poor functional vision were in paid employment (that is people who could not recognise the shapes of furniture in a room).



Only one in 10 people with the most severe sight loss were in paid employment

Blind and partially sighted people of working age were struggling financially

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

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 struggling financially.



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 they incurred as a result of their sight loss.



Almost half of 30–49 year olds struggle financially

Barriers to travel and transport remain a major issue for blind and partially sighted people, especially obstacles on the pavement

“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.”

A total of 40 per cent of blind and partially sighted people were not able to make all the journeys that they wanted or needed to, 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.

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

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

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

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

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

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.

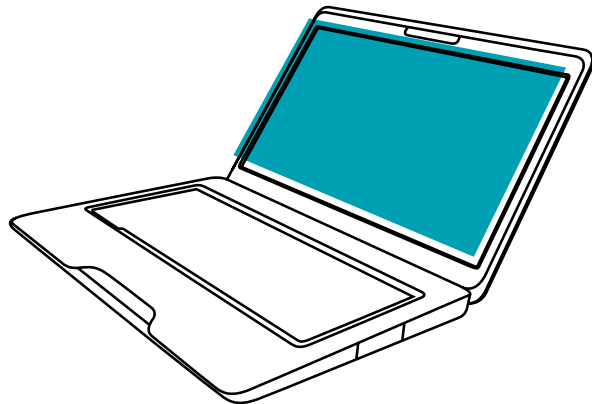
50%

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





For those aged 75 and over, almost two thirds did not use a computer, the internet, a tablet or a smartphone



One in four people reported 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

“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.”

Nine out of 10 blind and partially sighted people said that information on medication or food packaging was quite difficult or impossible to read. In terms of information provided by 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

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

Overall 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. For those aged 75 and over, almost two thirds did not use a computer, the internet, a tablet or a smartphone. The majority of people who do not currently use technology would like to use it if obstacles were removed.

40 per cent

said that information from health providers was never accessible

Public awareness and attitudes towards sight loss was poor

“[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.”

Over one-third of blind and partially sighted people said that they sometimes, frequently or always experience 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.



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 summer 2016 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

Research reports

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

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

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