My Voice: The views and experiences of registered blind and partially sighted people in the UK

A wakeup call to the realities of living with sight loss
Living with sight loss in the UK today is extremely tough. Whether you have recently lost your sight or have been blind for many years, all too often the reality is poverty, unemployment and social isolation.

This is the headline finding from the largest ever survey of the lives of blind and partially sighted people “My Voice”. But it does not have to be like this. If the right support was in place blind and partially sighted people could lead full and independent lives.

Facing Sight Loss Alone
Most people don't 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 are not enough eye departments in the UK with some kind of qualified support in place, and many of these posts are under threat. Sight loss advisers provide patients and their families with vital emotional and practical support and need to be funded on a sustainable basis.

People have to learn new coping skills and strategies, it is therefore vital that all patients have access to high quality and timely support at this extremely distressing time.

Support and rehabilitation services are essential for anyone with sight loss, but they’re often one step removed from providing people with the skills they need to be independent and to access and participate in their community. It can also reduce or prevent a person from needing far more costly care and support and these services need to be protected.

Fall in Employment Rates
It’s shocking that the proportion of blind and partially sighted people in employment has fallen from one in three in 2006 to one in four in 2015. It’s vital blind and partially sighted people have equal opportunities when it comes to employment. Government “welfare to work” schemes need to provide a much more tailored service for blind and partially sighted job seekers and there needs to be a sea change in employer attitudes. It’s also vital that funding for the Access to Work scheme that helps to meet the extra costs of employing someone who is disabled (such as a support worker or specialist equipment) is increased to keep pace fully with increasing numbers of participants.

There is also no scope for cutting the social security support that blind and partially sighted job seekers receive. Proposed changes to Employment and Support Allowance will create great hardship and reduce the likelihood of finding a job.

The research

My Voice aims 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 2006. However, the global recession, welfare reform, cut backs in public services and increased use of technology have all massively impacted upon the everyday lives of blind and partially sighted people in the last ten years.

My Voice 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.

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

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.

The findings presented within this report have been weighted so that they are representative 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.

Further research planned
My Voice is designed as a longitudinal study. This means that we will keep in touch with participants over the next few years (and beyond) to help us understand how the views and circumstances of blind and partially sighted people have changed over time.

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. Therefore, 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 such as people who are deaf blind or have complex additional needs, and those who do not speak English. This report will be available in mid 2016 from rnib.org.uk/myvoice

Key headlines

The nature of losing sight:
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 / registration.

Facing sight loss alone:
Most people don’t get any emotional support to help them adjust to losing sight and only a small proportion of people receive the practical support they need.

Fall in employment rates:
Blind and partially sighted people of working age in employment has fallen from 1 in 3 in 2006 to 1 in 4 in 2015.

Isolation:
Facing Sight Loss Alone:

My Voice shows 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 live alone.

Blind and partially sighted people today face low incomes, inaccessible information, difficulties in getting around, digital exclusion – all of which contribute to feelings of isolation.

The “My Voice” survey provides clear evidence that as a society we are failing blind and partially sighted people. Decisive action is needed to bolster their independence and ensure that they are able to live fulfilling lives.

Pazielet Hadi
Group Director, RNIB Engagement

Using My Voice for your work
This document gives only 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

The site also contains 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.

Age, amount of functional vision, age of onset of sight loss and additional disabilities can all have a major influence on someone’s experience.

Key headlines

The nature of losing sight:
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 / registration.

Facing sight loss alone:
Most people don’t get any emotional support to help them adjust to losing sight and only a small proportion of people receive the practical support they need.

Fall in employment rates:
Blind and partially sighted people of working age in employment has fallen from 1 in 3 in 2006 to 1 in 4 in 2015.

Isolation:
Four in every ten blind and partially sighted people feel cut off from people and things around them. Low incomes, inaccessible information, difficulties in getting around, digital exclusion, all contribute to feelings of isolation.

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