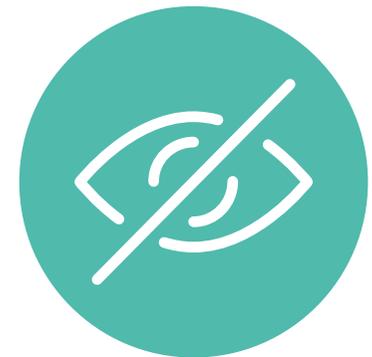




SIGHT LOSS

COMMUNITY HEALTH PROFILE

2022



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Foreword

The Sight Loss Community Health Profile was commissioned by Birmingham City Council to review the evidence on the sight loss community in Birmingham and nationally. The report synthesises evidence on the experiences, needs and outcomes of the sight loss community across a range of health and well-being indicators, including education, employment, housing, mental health, disabilities, substance (mis)use and physical activity. It illustrates the multi-layered barriers and inequalities faced by people with sight loss in relation to their health and everyday lives and highlights gaps in the existing evidence base. The report demonstrates the public health need for comprehensive monitoring, research, and engagement with sight loss communities at a local and national level.

The Sight Loss Community Health Profile is part of a wider series of evidence summaries produced by Birmingham City Council which focus on specific communities of interest.

Authored in partnership with Ken Easton

The Bayswater Institute

The BI is an independent research institute and registered charity, founded in 1990.



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Community Evidence Summary

As part of the Public Health Divisions' work to improve the understanding of the diverse communities of Birmingham, we are developing a series of short evidence summaries to improve awareness of these communities and their needs.

The common objectives for each of the evidence summaries are:

- To identify and summarise the physical health, mental health, lifestyle behaviour, and wider determinants of health-related issues affecting the specific community both nationally and locally.
- To identify and summarise gaps in knowledge regarding the physical health, mental health, lifestyle, behavioural and wider determinants of health-related issues that may be affecting the specific community both nationally and locally.
- To collate and present this information under the ten key priority areas identified in the Health and Wellbeing Strategy for Birmingham 2021.
- To engage with the local communities on the evidence found and any gaps.
- To promote the use of these summaries for Local Authority and wider system use for community and service development.



Executive Summary

Sight loss is a significant health issue that affects many people. In England, there were estimated to be 656,000 people with moderate to severe sight loss in 2021. In Birmingham, the estimate was 28,100. Sight loss can affect anyone at any stage of their life, and it is estimated that one in five will start to live with sight loss during their lives. 50% of sight loss could have been treated if detected early. Screening for eyesight problems is recommended for everyone every two years, and major screening programmes are in place. In 2016/17, 12,995,512 NHS eyesight tests were conducted: 697,504 in Birmingham and the Black Country. This represents approximately 60% of the number of tests needed each year and leaves many people with possible eye defects that may deteriorate and become untreatable. In Birmingham, it is estimated that the total cost of sight loss, including direct and indirect costs, is £380,200 each year. Amongst the groups with the lowest take-up rates for screening are people with learning disabilities and autism, older people with dementia, people from deprived communities and people from Black and Minority Ethnic communities.

The major eye diseases that cause severe sight loss in the UK are AMD (Age-related Macular Degeneration), Cataracts, Glaucoma and Diabetic Retinopathy. There are 8,620 people registered blind or partially sighted in Birmingham, and 471 Certificates of Visual Impairment were issued in 2016/17. People who are blind or partially sighted have great difficulty engaging in everyday community life and tend to lead isolated and sedentary lives: 40% say they are moderately or completely cut off from their local community. They tend to have lower attainment levels at school, with only one in four of working age being in employment. They also have major mobility problems both on foot and using public transport, and they often suffer financial hardship. They have difficulty taking physical exercise

and often have a poor diet, resulting in poor physical fitness, which can lead to further eye problems. COVID has made isolation and loneliness an even greater problem for people with severe sight loss, and the incidence of mental health problems, especially depression, is high. 70% of people with severe sight loss are over 65, and the incidence of sight loss increases with age until it is 1 in 2 for the over 90s. Sight loss is frequently associated with other serious health problems, including learning disabilities and autism, dementia, diabetes and strokes, and people with severe sight loss have shorter life expectancy because of the link with other conditions.

The gaps and inequalities that this review reveals are:

- The gap in the number of eye-sight screening tests that are needed and are undertaken, with some communities, in particular, having low take-up rates.
- Problems of mobility on foot and on public transport mean that people with sight loss have difficulty engaging in community life.
- There are low levels of physical activity amongst people with sight loss and they have difficulty following a good diet. Together these factors lead to poor physical fitness levels.
- People with sight loss have fewer opportunities to become self-sufficient and independent through educational attainment, employment, and financial security.
- People with sight loss have low levels of emotional well-being and whilst there is support with medical care and physical rehabilitation, support for emotional wellbeing may be less available.

- Sight loss is associated with autism and dementia, and support for multiple long-term conditions may be fragmented.
- The elderly are most at risk of severe sight loss, resulting in them becoming more isolated, lonely, and more prone to mental health problems.
- People with sight loss in some communities are more at risk than others. These include: the most deprived areas, Black and Minority Ethnic communities, people with learning disabilities and autism and the elderly with dementia.
- The COVID pandemic has caused even greater isolation and loneliness and made access to health and community services even more difficult for people with sight loss with consequential increases in mental health problems.



Methodology

Sight loss is one of the most prevalent health problems in the world. As a result, there is an extensive database on sight loss covering prevalence statistics and causes and treatments for every kind of sight loss impairment. To identify relevant sources, search terms were narrowly defined and made specific to each section of the report. Although some use was made of general databases, the main focus was databases specialized in sight loss. Apart from those included in the Introduction, all references to studies conducted outside the UK were excluded.

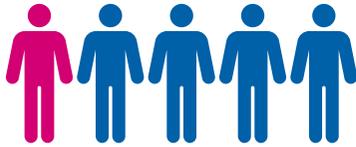
For the demographic section, the search terms used were 'sight loss' or 'visual impairment' and 'statistics' or 'prevalence' and 'world' or 'global' or 'UK' and 'Birmingham'. Searches were undertaken using PubMed and Google Scholar and the specialist databases of:

- The World Health Organisation <https://www.who.int/news-room/fact-sheets/detail/blindness-and-visual-impairment>
- The RNIB Sight Loss Tool <https://www.rnib.org.uk/professionals/knowledge-and-research-hub/key-information-and-statistics/sight-loss-data-tool>
- The International Agency for the Prevention of Blindness <https://www.iapb.org/>
- The Vision Loss Expert Group of the Global Burden of Disease Study. <https://www.globalvisiondata.org/>

- NHS Digital
- Public Health England
- Office of National Statistics

For all other sections, searches were specific to the topic, e.g. 'sight loss' or 'visual impairment' and 'employment' or 'education. To locate literature on particular eye conditions, 'sight loss' was replaced with the relevant term, e.g. 'cataracts' or 'blindness'. A key source of statistics was the RNIB Sight Loss Tool which records data for 209 sight loss indicators at national and local authority levels. The RNIB website was also an important means of accessing the grey literature associated with the management of sight loss. Statistics for Birmingham were also accessed from the RNIB summary of statistics for Birmingham and the English Vision Strategy Evidence Base for Birmingham and Solihull.

Sight loss can affect anyone at any stage of their life, and it is estimated that



1 IN 5 WILL START TO LIVE WITH SIGHT LOSS DURING THEIR LIVES

THE MAJORITY OF PEOPLE WITH VISION IMPAIRMENT AND BLINDNESS ARE

OVER THE AGE OF 50



however, vision loss can affect people of all ages

LEARNING DISABILITIES

Adults with learning disabilities are

10x MORE LIKELY TO BE BLIND OR PARTIALLY SIGHTED



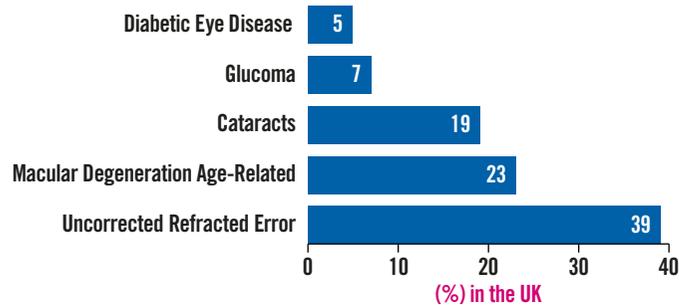
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1.0 Introduction

1.1 Overview of Sight Loss

Sight loss is one of the significant health issues in the world. It affects millions of people, can impact anyone and can become an issue at any stage in life. It is caused by various eye and brain disorders and has different degrees of severity. These range from a need to wear spectacles to correct a refractive error in the eye to complete blindness. In developed countries, advances in medicine mean that many eye diseases can be successfully treated. National health and social care systems also exist to detect sight loss, provide appropriate treatment and help patients manage their condition when sight loss is severe. This profile begins by describing the major forms of eye disease and the degrees of severity of eye disease. After a brief review of the prevalence of sight loss around the world, it focuses on the prevalence of different forms of sight loss in England and Birmingham. The profile then reviews the issues caused by sight loss for people at different stages of their lives in England and Birmingham and the support they receive from the health and social care systems and other institutions in society.

MAIN CAUSES OF SIGHT LOSS



↑ 17%
ESTIMATED INCREASE IN SIGHT LOSS NUMBERS IN THE UK BY 2030



42,000
INPATIENT EYESIGHT PROCEDURES CONDUCTED IN BIRMINGHAM (2019/20)
AND OVER 400,000
OUTPATIENT APPOINTMENTS

Risks of specific eye disease higher amongst certain communities

4-8x higher risk of Glaucoma and a higher risk of Diabetic Eye Disease in Black African & Caribbean individuals

3x higher risk of Diabetic Eye Disease in the South Asian Community



HIGHER RISK of Cataracts in the Asian Community

1.2 Causes of Sight Loss

Sight loss can take many forms and has different degrees of severity. The main forms of visual impairment that cause severe sight loss are listed in the following table. The table also provides information about the prevalence of these conditions in Birmingham:

Table 1: The eye diseases that cause severe visual impairment in the UK

Age-related macular degeneration (AMD)	Commonly affects people over the age of 50 and is the leading cause of blindness. There are two main types of AMD:
	<ul style="list-style-type: none"> Wet AMD can develop quickly, affecting central vision in a short period. Early identification and treatment of wet AMD are vital. Treatment can halt further development of scars, but lost sight cannot be restored. Dry AMD can develop slowly, taking a long time to progress. There is currently no treatment for dry AMD. People with early and moderate stages of dry AMD are not eligible for registration, but it impacts daily life; for example, a person may have to stop driving. In Birmingham, it is estimated that: <ul style="list-style-type: none"> 36,700 people are living with the early stages of AMD; 2,710 are living with late-stage dry AMD; 5,620 are living with late-stage wet AMD; 7,910 combined late-stage AMD.
	Between 2018 and 2030, RNIB estimates an increase of 18% in Birmingham's number of people living with late-stage AMD.

Cataracts	<p>A common eye condition prevalent in older people. The lens becomes less transparent and turns misty or cloudy. Cataracts, over time, can get worse and impact vision. A straightforward operation replaces the lens with an artificial one. Numerous studies have demonstrated the cost benefits of cataracts surgery in improving life quality and reducing the number of falls. In Birmingham, it's estimated that 8,640 people are living with cataracts. Between 2018 and 2030, there is estimated to be an increase of 19% in the number of people living with cataracts in Birmingham.</p>
Glaucoma	<p>A group of eye conditions in which the optic nerve can be damaged due to changes in eye pressure. Damage to sight can usually be minimised by early diagnosis and careful regular observation and treatment. Many glaucoma patients will attend regular appointments and take eye drops for the rest of their lives to prevent deterioration of vision. Some forms of glaucoma can be treated with laser surgery and surgery. RNIB estimates that 19,800 Birmingham citizens are living with ocular hypertension. A further 8,950 people are living with glaucoma. Between 2018 and 2030, there is estimated to be an increase of 16% in the number of people living with glaucoma in Birmingham.</p>
Diabetic Eye Disease	<p>People with diabetes are at risk of diabetic eye disease, which can affect the blood vessels in the eye. This can lead to permanent sight loss. Screening and early diagnosis with appropriate intervention are essential. RNIB estimates in Birmingham:</p> <ul style="list-style-type: none"> • 61,300 adults have been diagnosed with diabetes. • 21,600 people are living with diabetic retinopathy. <p>Of these, 1,990 have severe diabetic retinopathy, a later stage of the disease that is likely to result in significant and potentially certifiable sight loss³⁸. Between 2018 and 2030, there is estimated to be an increase of 8% in the number of people living with diabetic retinopathy in Birmingham</p>

Source: WHO¹ and RNIB Sight Loss Data Tool v 4.3.¹²

1.3 Measure of Severity

The International Classification of Diseases classifies the degree of vision impairment in two groups, distant and near vision impairment³:

Table 2A and 2B: The severity of visual impairment

Table 2A: Near Visual Impairment

Description of Impairment	Measure
Near Vision Impairment	Near visual acuity worse than N6 or M.08 at 40cm.

Table 2B: Distant Visual Impairment

Description of Impairment	Measure
Mild	Visual acuity worse than 6/12 to 6/18
Moderate	Visual acuity worse than 6/18 to 6/60
Severe (or Low Vision or Partially Sighted)	Visual acuity worse than 6/60 to 3/60
Blindness	Visual acuity worse than 3/60

Source: Vision Loss Expert Group⁴

The terminology used to describe different categories of visual impairment is variable, particularly for severe forms, also known as low vision or partially sighted. In this profile, except for section 7, which reports detection in the whole population, the focus will be on people with severe sight loss, for whom the terms blind and partially sighted or low vision are most frequently used. Visual acuity is recorded as a fraction with the numerator indicating the test distance of the chart in feet. The denominator indicates the distance at which a 'normal' eye could see the smallest letters that the eye being tested can see.

1.4 The Detection of Sight Loss

The World Health Organisation⁵ estimates that globally at least 2.2 billion people have a near or distant vision impairment. In at least 1 billion (50%) of these cases, vision impairment could have been prevented or has yet to be addressed. The leading causes of vision impairment and blindness are uncorrected refractive errors and cataracts.

Prevention of avoidable sight loss is recognised as a key priority for the WHO's global initiative to eliminate avoidable blindness by 2020 – Vision 2020 – The Right to Sight⁶, to which the UK is a signatory. This is also a key priority for Vision UK and is a particularly important issue in the ageing population.

The majority of people with vision impairment and blindness are over the age of 50 years; however, vision loss can affect people of all ages. It is estimated that, in 2020, 33.6 million people over the age of 50 were or could be classified as blind. 15 million (43%) of these cases were caused by cataracts⁷. In 2020, there were estimated to be 206 million people over 50 with mild or severe vision impairment globally. The leading cause is an uncorrected refractive error, with an estimated 86 million cases globally (42% of all cases).

Detecting sight loss must be undertaken at all stages of life and is a major industry in the developed world. There are 13 million NHS eye tests each year in England, leading to eight million outpatient appointments and 800,000 inpatient procedures to treat and prevent sight loss⁸.

The main causes of sight loss in the UK are:

- Uncorrected refracted error (39%)
- Age-related Macular Degeneration (AMD) (23%)
- Cataract (19%)
- Glaucoma (7%)
- Diabetic eye disease (5%)

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1.5 Referrals, Diagnosis and Treatment

There are over eight million NHS outpatient appointments in eye clinics and ophthalmology departments in the UK every year and over 880,000 inpatient procedures (for cataracts and other surgical procedures) each year⁹. In Birmingham, in 2019/20, there were 397,835 outpatient appointments and 41,965 inpatient procedures¹⁰. The study¹¹ of five communities that explored issues of accessing sight tests also explored the experiences of people being referred for treatment of glaucoma and diabetic retinopathy. The main problems identified were:

- Complex referrals processes that involved many services and sometimes long waiting times for appointments
- Fragmented service delivery in which patients rarely saw the same clinician twice
- Complex data management processes in which patients were often asked to repeat the same information on many occasions
- A failure to recognize the difficulties and needs of people from minority ethnic communities

Access to a person who could help patients navigate the health system was seen as the most pressing need, and, where they were available, ECLOs (Eye Clinic Liaison Officers) were seen as fulfilling this function.

The people most likely to suffer severe sight loss are as follows:

- The elderly, particularly people with dementia or who have had strokes.
- People from the Black and Minority Ethnic communities. A research review of studies of sight loss in ethnic communities reports rates of sight problems of 61% for African-Caribbean and 53% for Asian people compared with an older white population at 52%¹². Asian and Black ethnic groups are at greater risk of eye diseases (such as glaucoma and diabetic retinopathy) than other ethnic groups and are more likely to go blind.¹³

- Two-thirds of the people with sight loss are women.
- Adults with learning disabilities are ten times more likely to be blind or partially sighted.
- People on low incomes who, because of worries about costs, for example, the costs of spectacles, do not come forward for eyesight screening.
- People with diabetes are at risk of developing diabetic retinopathy.
- There are more than 25,000 blind and partially sighted children under 16 in the UK. It is estimated that half of these children have other disabilities^{14, 15}.

People from some ethnic communities are at greater risk of some of the leading causes of sight loss^{16, 17}:

- Black African and Caribbean people are four to eight times more at risk of developing glaucoma compared to white people
- Within the Asian community in the UK, there is a much higher incidence of age-related cataracts when compared to white people
- The risk of diabetic eye disease is around three times greater in South Asian people compared to white people
- Black African and Caribbean people are also at a higher risk of diabetic eye disease.

1.6 Preventable Eyesight Problems

Despite the many eyesight tests undertaken each year, at least 50% of eye problems go undetected. This estimate is based on the number of people with sight loss that could have been prevented.

The RNIB¹⁸ estimates there were 28,199 NHS sight tests per 100,000 population in the Birmingham and Black Country area during 2015/ 2016,

which is above the rate for England (23,925)¹⁹. These figures exclude any tests undertaken privately. To meet the recommendation of 50% of the population having an eyesight test every year, 50,000 per 100,000 would be needed. In Birmingham, in 2015/2016, there was a shortfall of more than 40% in the number of tests undertaken. The RNIB²⁰ estimated that, in 2017, approximately 25% of the UK population who were due for an eyesight test did not take one.

The majority of preventable eye problems are refraction issues for which prescription spectacles can provide a remedy. It is estimated²¹ that almost 59% of the UK population wear prescription spectacles and that approximately 3.8 million pairs of spectacles were sold in 2020.

Of the major eye diseases that can cause blindness or severe sight loss but are preventable, the Public Health Outcomes Framework²² provides information on the rate of Certificates of Visual Impairment (CVIs) for three leading causes. In Birmingham:

- The age-related macular degeneration (AMD) rate was 98 CVIs per 100,000 people over 65 years. For England, the rate was 105. The RNIB²³ estimates that 8,380 people have either wet or dry AMD in Birmingham in 2021.
- The rate of glaucoma was 9 CVIs per 100,000 people over 40 years. For England, the rate was 13. The RNIB estimates that 9,090 people have glaucoma in Birmingham in 2021.
- The rate of diabetic eye disease was 5 CVIs per 100,000 people over 12 years. For England, it was 3. The RNIB estimate 2,010 have severe diabetic retinopathy in Birmingham in 2021

The RNIB²⁴ estimates that 8,740 have treatable cataracts in Birmingham in 2021.

1.7 The Economic Cost of Sight Loss

Vision impairment poses an enormous global financial burden, with the annual global costs of productivity losses associated with vision impairment from uncorrected myopia and presbyopia alone estimated to be US\$ 244 billion and US\$ 25.4 billion²⁵. It is estimated that 84% of the economic costs of sight loss lie outside the costs to health and social care systems, reflecting the difficulties people with severe sight loss face in being financially active.

It is estimated that the total costs of eye health and sight loss in the UK are £28 billion per year²⁶. The direct costs of providing eye health care are estimated to be £3 billion per year. Indirect costs from other wellbeing issues, lower employment rates, implications for family members etc., are estimated to be £25 billion. In Birmingham, the total cost of eye health, including direct and indirect costs, is estimated to be £380.2 million per year²⁷.

1.8 The Social Impact of Sight Loss

The social impact of severe sight loss is extreme: people who are blind or have very low vision have great difficulty engaging in most normal activities in their homes or the community. Only 1 in 4 people registered blind or partially sighted are employed²⁸, and many suffer financial hardship. Many people live isolated lives: 40% in England say they are moderately or completely cut off from their local community²⁹. Supporting people with severe sight loss also has a major impact on others: in addition to funded support, family and friends contribute hundreds of thousands of unpaid hours each year in caring roles.



28,600 people living in Birmingham who have some degree of sight loss
 NATIONAL FIGURE IS **656,000**

10,090 people living in Birmingham who are blind or partially sighted
 NATIONAL FIGURE IS **245,000**

GLOBAL SIGHT LOSS
 WORLDWIDE THERE ARE ROUGHLY
2.2 BILLION



PEOPLE LIVING WITH SIGHT LOSS

Based on global data from 2018

1 billion of those have preventable and treatable sight loss. There are 33.6 million people globally who could be classified as blind

9,015 People in Birmingham with Certificates of Visual Impairments (CVIs) (2016/17)
 NATIONAL FIGURE IS **290,500**

£380.2 MILLION

Total annual direct and indirect costs of sight loss in Birmingham



THE FIGURE FOR THE UK REACHES **£28 BILLION**

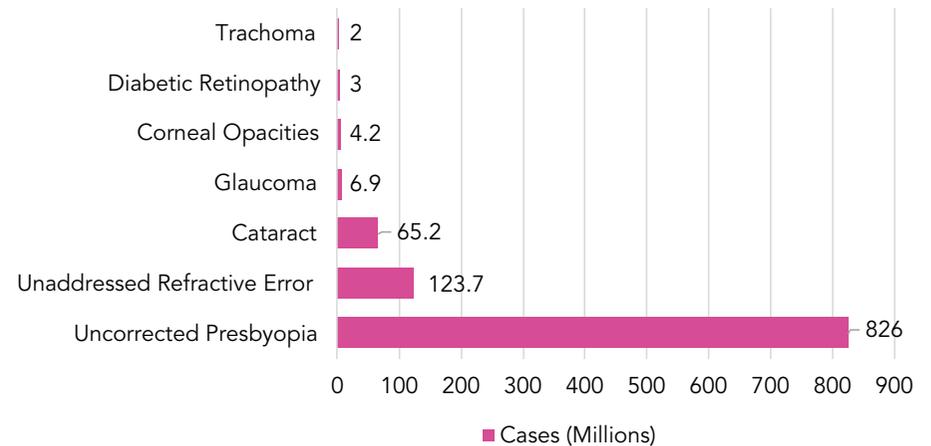
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1.9 The International Context

Over one billion people across the globe are considered to have moderate or severe distance vision impairment or blindness that has been unaddressed. If they had been detected at an early stage, they could have been treated, and in the majority of cases, sight loss would have been avoided or its effects mitigated.³⁰

The most prevalent unaddressed visual impairments in the world are listed in figure 1 (see Appendix 2 for full data).

Figure 1: Unaddressed Visual Impairments



Source: World Health Organisation³¹ and Fricke et al. 2018³²

The major categories of visual impairment globally are unaddressed refractive error and uncorrected presbyopia (the loss of ability to focus on nearby objects). Both are correctable in the developed world by the prescription of spectacles. Cataracts are also a major problem in many underdeveloped parts of the world, a condition corrected by a relatively straightforward operation in the developed world.

There are considerable differences in the prevalence of sight impairment diseases across the globe. The prevalence of distance vision impairment in low- and middle-income regions is estimated to be four times higher than in high-income regions³³. For near vision, unaddressed near vision impairment rates are estimated to be greater than 80% in Western, Eastern and Central Sub-Saharan Africa. In contrast, comparative rates in high-income regions of North America, Australasia, Western Europe, and Asia-Pacific are lower than 10%³⁴. The prevalence of diseases across countries varies according to the availability of eye care services, their affordability, and the eye care literacy of the population. For example, the proportion of vision impairment attributable to cataracts is higher in low- and middle-income countries than in high-income countries. In high-income countries, diseases such as glaucoma and age-related macular degeneration (AMD) are more common. Among children, the causes of vision impairment vary considerably across countries. For example, congenital cataract is a leading cause in low-income countries, whereas, in middle-income countries, it is more likely to be retinopathy of prematurity. As in adult populations, the uncorrected refractive error remains a leading cause of vision impairment in all countries amongst children^{35 36}.

The incidence and types of sight loss in the United Kingdom do not follow the dominant world pattern found in low- and middle-income countries. This report will focus on statistics and research on the forms of sight loss prevalent in the UK.

A systematic review³⁷ of progress in combating sight loss worldwide concluded that improvements in eye care services are succeeding in reducing the prevalence of profound sight loss. Still, rising populations and ageing populations will mean that the prevalence of severe eye disease is predicted to increase in the next 30 years. In particular, increases in the prevalence of two conditions associated with ageing, glaucoma and AMD (age-related macular degeneration), are predicted to increase significantly.

The RNIB forecast that there will be an increase of 17% in the number of people with severe sight loss in the UK by 2030³⁸. In Birmingham, the RNIB forecast that by 2030 there will be an increase of 18% in AMD cases, 19% in cataracts, 16% in glaucoma and 8% more cases of Diabetic Eye Disease³⁹.



1.10 The National and Local Context

One in every five people in the UK will start to live with sight loss in their lifetime⁴⁰. The International Agency for the Prevention of Blindness (IAPB) estimates that 4.3 million currently have some degree of vision loss in the UK (6.4% of the population), of which 170,00 are blind⁴¹. The Thomas Pocklington Trust estimates that 1.87 million people in the UK live with sight loss⁴².

The Royal National Institute for Blind people (RNIB) provides the following estimates of sight loss numbers in England⁴³ and Birmingham⁴⁴. In 2021, the estimated prevalence of sight loss in Birmingham was 2.5%, slightly lower compared to the national (3.2%). The prevalence is projected to remain the same in 2025. Table 3 shows the estimated prevalence of types of sight loss (2021 and 2025) in Birmingham compared to National estimations.

Table 3: Current and Estimated Sight Loss Numbers in England and Birmingham

Sight Loss Indicators	England (2021)	England (2025)	Birmingham (2021)	Birmingham (2025)
mild sight loss	1,190,000	1,290,000	18,500	19,760
moderate sight loss (partial sight)	411,000	443,000	6,380	6,760
severe sight loss (blindness)	245,000	271,000	3,710	3,960
total no. with sight loss	1,840,000	2,000,000	28,600	30,400
% of people with sight loss c.f. overall population	3.2%	3.2%	2.5%	2.5%
Rate of people with sight loss per 1,000	32	N/A	25	N/A

Source: RNIB Sight Loss Data Tool v4.3.1 England and Birmingham^{45 46}

There are wide variations in estimates of the current number of people in the UK with sight loss, which reflects different ways of making estimates and the difficulty of making such estimates when many people have not been screened for sight loss.

There are more reliable and agreed figures for the smaller number of people screened and certified with a visual impairment.

In England, 276,690 were registered blind or partially sighted in 2019/20, and 193,490 were over 65 (69.93%). In Birmingham in 2019/20, of the 9,015 people registered blind or partially sighted, 6,295 were over 65 (69.83%). 13% of the population of Birmingham are 65 or over^{47 48}.

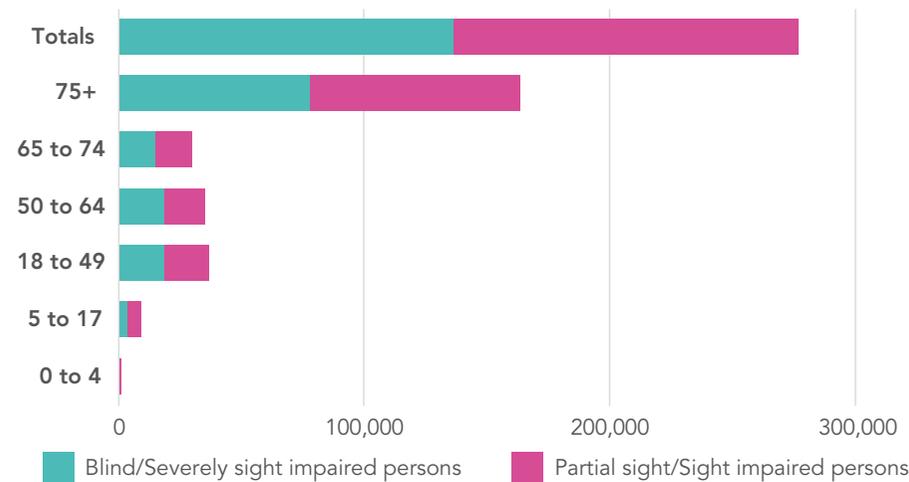
The proportion of people with severe sight loss increases with age after 60. RNIB estimate that:

- 1 in 8 over 60 have sight loss
- 1 in 5 over 75 have sight loss
- 1 in 2 over 90 have sight loss⁴⁹

It is estimated that at least half of sight loss is avoidable. There are 16 million NHS eye tests each year, eight million outpatient appointments and 800,000 in patient procedures to treat and prevent sight loss⁵⁰.

The main factor affecting who has sight loss is age. The older people are, the more likely they have sight loss. The age distribution of people who are blind or have severely impaired sight and people who have partial sight in England in 2019/20^{51 52} can be seen by figure 2 below (see Appendix 3 for full data).

Figure 2: Age distribution for Blind and Partially Sighted People in England



Source: NHS Digital⁵³

1.11 Sight Loss in Birmingham

In Birmingham, there are estimated to be 28,600 people living with sight loss⁵⁴. This includes:

- 3,710 people living with blindness.
- 24,880 people living with partial sight.

The estimated prevalence of sight loss is lower in Birmingham than the average for England, with 2.5% of the population living with sight loss compared to 3.2% nationally⁵⁵.

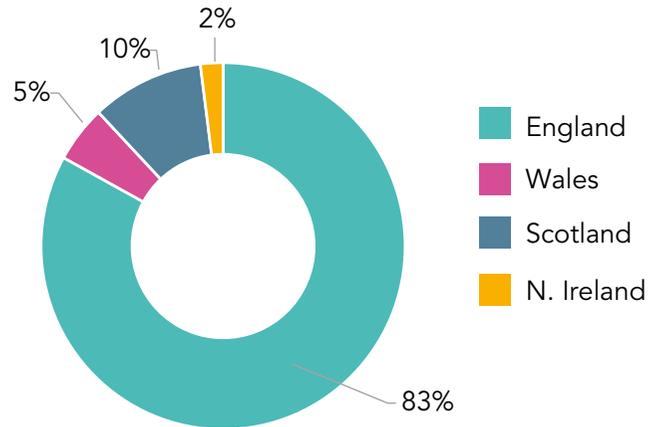
1.12 Registration and Certificates of Vision Impairment (CVI)

A Certification of Vision Impairment (CVI) certifies that a person has been assessed for sight loss and is either partially sighted or blind. A CVI provides a route to request social care services. The number of CVIs recorded provides an official record of the prevalence of severe sight loss. It is an underestimate of the total number of people with significant sight loss because (a) many people with sight impairment may not have been assessed, and (b) many who have been assessed may not reach the criteria for certification although their sight loss may have important lifestyle consequences, for example, not being allowed to drive.

In the UK in 2017⁵⁶, there were 350,000 people with CVIs. 173,735 were classed as severely sight impaired, and 176,126 were classed as sight impaired. Figure 3 shows the distribution of people with CVIs across the UK (see Appendix 4 for full data).



Figure 3: Distribution of Certificate of Visual Impairments Across the UK



Source: NHS Digital⁵⁷

Over 24,000 people are given a CVI each year in England and Wales, but the number of new registrations in England has decreased by 29% in recent years^{58 59}.

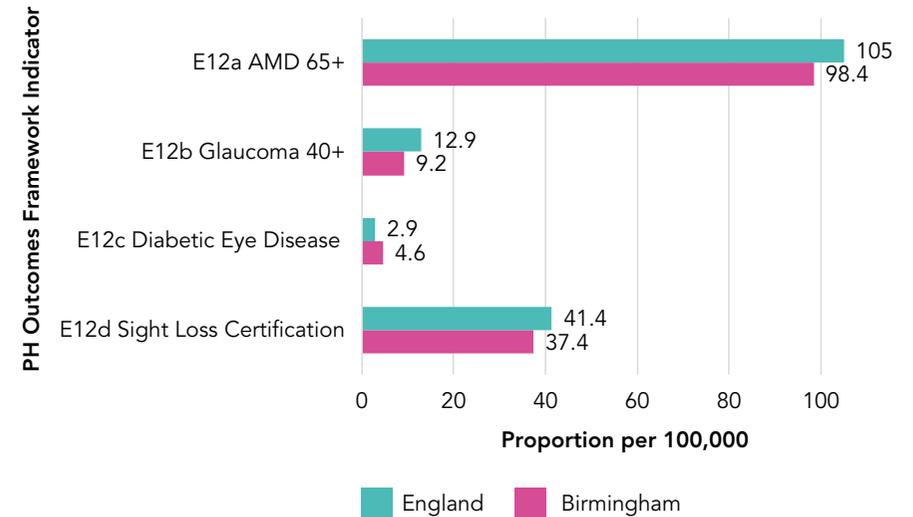
Although the CVI permits referral to social services, only 1 in 3 registered blind and partially sighted people were offered mobility training, and 1 in 5 received practical help around the home⁶⁰.

In Birmingham, there are 9,015 people registered blind or partially sighted. (790 registered blind or partially sighted people per 100,000 population)⁶¹. This is higher than the overall rate for England. From 2017 to 2020, there has been an increase of 5% in the overall number of people registered as blind or partially sighted.

In Birmingham, 37 CVIs were issued per 100,000 people, compared to 41 per 100,000 people in England⁶². In 2019/20, 427 Certificates of Vision Impairment were issued in Birmingham. This was similar to the overall rate for England.

Figure 4 below shows the sight loss rate certifications and the rates for three eye diseases in 2019/20 in Birmingham and England.⁶³ (see Appendix 5 for full data)

Figure 4: Preventable Sight Loss Indicators 2019/20



Source: Public Health Outcomes Framework

In all cases except Diabetic Eye Disease, the figures for Birmingham are below the rate for England. The total number with Diabetic Eye diseases in Birmingham is relatively small.

Registered blind or partially sighted by age band

The main factor determining who is registered blind or partially sighted in Birmingham and Solihull is age⁶⁴. The Public Health Outcomes Framework⁶⁵ compares two age categories between Birmingham and England.

Predicted eye disease and trends

Many people live with conditions that could lead to sight loss, and the number with these conditions is estimated to increase significantly in the next decade⁶⁶.

The estimated number of people who will be living with sight-threatening eye conditions in Birmingham from 2021 to 2030⁶⁷ are shown in table 4.



Table 4: Predicted Numbers Living with Sight Loss Conditions in Birmingham

Sight Loss Cause	2021	2025	2030
Early-stage AMD	37,400	39,900	42,900
Late-stage dry AMD	2,720	2,900	3,190
Late-stage wet AMD	5,660	6,050	6,660
Total late-stage AMD	7,960	8,510	9,360
Cataract	8,740	9,350	10,300
Ocular hypertension	20,000	20,900	21,800
Glaucoma	9,090	9,660	10,400
Diabetes	62,100	64,900	68,100
Diabetic retinopathy	21,800	22,500	23,300
Severe retinopathy	2,010	2,070	2,140
Totals	169,100	177,690	188,300

Key: AMD Age-related Macular Degeneration

Source: RNIB Sight Loss Data Tool Version 4.3:1 Birmingham⁶⁸

SIGHT LOSS AT BIRTH

According to a study of 439 babies born in the UK



550 CHILDREN IN BIRMINGHAM (2021) AGED 0-16 WHO ARE BLIND OR PARTIALLY SIGHTED

GROWING UP WITH SIGHT LOSS



LOWER LEVELS OF ACADEMIC ATTAINMENT



LOWER LEVELS OF PHYSICAL ACTIVITY



HIGHER RATES OF OBESITY

A BOLDER HEALTHIER BIRMINGHAM

2.0 Community Profile

2.1 Getting the Best Start in Life

Getting the Best Start in Life Key Findings:

- In 2021, an estimated 25,000 and 550 children aged 0-16 are visually impaired in the UK and Birmingham respectively.
- 15,555 of the children nationally, and 495 in Birmingham have special needs statements.
- 1,208 pupils nationally and 99 in Birmingham were in SEND settings.
- 495 children in the UK were born blind or with severe visual impairment.
- 10% die within one year of diagnosis.

2.1.1 Prevalence of Sight Loss in children

Over 25,000 visually impaired children aged 0-16 are in the UK, and around 15,000 are aged 17 to 25⁶⁹ ⁷⁰. Approximately half of these children will have additional disabilities and special educational needs. This figure includes:

- children who are registered blind or partially sighted
- children living with sight loss but who are not registered blind or partially sighted.

A statement of special educational needs (SEN) is issued to children to set out any additional help required in the education setting. In England in 2021, there were 16,555 pupils with a statement of special educational needs (SEN) or education, health and care (EHC) plans with vision impairment as their primary support need. Of these pupils, 8,486 were in primary school, 6,861 were in secondary school, and 1,208 were in special schools⁷¹.

In Birmingham in 2021, there were 495 pupils with a statement of special educational needs (SEN) or education, health and care (EHC) plans with vision impairment as their primary support need. Of these pupils, 196 were in primary school, 200 were in secondary school, and 99 were in special schools⁷².

In Birmingham⁷³, in 2021, there were an estimated 550 blind and partially sighted children aged 0-16 and 350 blind and partially sighted young people aged 17-25.

Table 5: Estimated number of blind and partially sighted children by age group in Birmingham

Age group	Blind	Partially sighted	Total
0 to 16 years	140	410	550
17 to 25 years	90	260	350

Source: RNIB Sight Loss Data Tool v.4.3.1

2.1.2 Levels of Sight Loss in Children

Severe visual impairment and blindness in children (SSI)

In a study of 439 UK children born in 2000⁷⁴ newly diagnosed with severe visual impairment or blindness, most were diagnosed in the first year of life:

- Prenatal causes affected 268 (61%)
- 336 (77%) had additional impairments and

- At least 331 (75%) had disorders that were neither preventable nor treatable with current knowledge.
- 44 (10%) of the children died within one year of diagnosis.

The causes of children having severe visual impairment as listed in SSI Certifications in England and Wales in 2009/10 were primarily related to the brain: cerebral visual impairment and optic nerve disorders⁷⁵. The incidence of severe visual impairment or blindness was associated with low birthweight or premature birth, learning disorders, and ethnic minorities.

Sight Impairment in Children (SI)

The causes of children having partial visual impairment as listed in SI Certifications in England and Wales in 2009/10 were primarily associated with the eye: congenital globe anomalies (18.4%) and retinal dystrophy (16.6%)⁷⁶. They were similarly associated with low birthweight or premature birth, learning disorders, and ethnic minorities.

2.1.3 Screening for Children

In addition to children with severe visual impairment, many others may have undetected visual problems, especially in at-risk groups such as those with learning disabilities⁷⁷. An analysis of parental reports of the prevalence of eye problems in 14,961 UK 3-year-old children found that 881 (5.7%) reported eye problems but only 45 (0.24%) reported visual impairment⁷⁸. Eye disorders with visual impairment were associated with lower socioeconomic status, decreasing birthweight and prematurity. Visual impairment was more likely in those of low birthweight and from an ethnic minority group.

The UK National Screening Committee recommends universal vision screening for all children between the ages of 4 and 5 years in school. It is led by orthoptists (specialists trained in children’s vision screening)⁷⁹. However, there is evidence that screening in schools is patchy across the UK. There is a high prevalence of visual problems among children with special needs, and a

study of screening in 44 special schools in Wales found that 42% of pupils had received no screening⁸⁰. When the screening was undertaken, 51% had some abnormality that warranted action to prevent risk to sight.

In Birmingham, the school entry vision screening service undertakes an eye test for every child during their reception year⁸¹. It is offered in every primary school in Birmingham, including special schools and religious schools. At this test, the child's eyes are tested for squints, coordination between the two eyes, and problems with vision.

2.1.4 Growing up with Sight Loss

There is a higher prevalence of children with visual impairment being overweight and obese compared with children with no reported visual impairment of similar age and gender. A systematic review of 29 studies⁸² confirmed this finding and concluded that this resulted from lower levels of physical activity and higher levels of calorific intake. Studies within the review found that children with visual impairment engaged in less physical exercise at school than their peers. Children with sight loss experience many difficulties in education, and at both primary school and secondary school levels, they record lower levels of achievement than their sighted counterparts. They can also be deprived of many other opportunities, such as sports and recreation⁸³.

Most blind and partially sighted children are educated in inclusive (mainstream) education⁸⁴. A Visual Impairment (VI) Service supports children in schools but is organised differently by local authorities across the country⁸⁵. The VI Service provides support for accessing learning materials and mobility training. Still, many resourcing issues exist, and blind, and partially sighted children are increasingly deprived of their specialist support⁸⁶. As a result, learning materials and exams are not consistently available in alternative formats suitable for the visually impaired⁸⁷.

In Birmingham, the Access to Education service includes a Sensory Support service for children and young people with a visual impairment aged up to 25 years⁸⁸. Early years support is provided by My Care in Birmingham. Birmingham City Council also offers free habilitation (mobility and independent living skills) training for children and young people with a visual impairment from age two to eighteen. Charities also provide support, for example, Guide Dogs' Children and Young People Services.

There are two educational establishments (one school and one college) that provide specialist education for children with sight loss in Birmingham⁸⁹.

Priestly Smith School (located in Great Barr) provides education for visually impaired children aged two to nineteen years old. Children will have (or be in the process of getting) a Statement of Special Educational Need or Education Health Care Plan in which vision is listed as a significant need. All teaching staff are qualified teachers of the visually impaired.

Queen Alexandra College in Harborne provides educational, vocational and life preparation courses for young people aged 16-25 with a visual impairment and/or additional disabilities. Courses are full time, and residential accommodation is available. The college accepts students from Birmingham and nationwide. The school shares its campus with several mainstream schools. This means that pupils can benefit from mainstream education with fully sighted children and have access to a full range of sports facilities as well as a specifically tailored education involving hands-on experiences, Braille teaching, specialist ICT teaching, touch-typing, mobility training and an accredited programme for the delivery of Independent Living Skills. Children are also entered for the end of school exams such as GCSEs, and they can take part in several extracurricular activities. Ex-pupils also benefit from access to a support group for them.

22-38% of people with severe sight loss show symptoms of clinical depression

31% OF PEOPLE WITH SEVERE SIGHT LOSS HAVE PESSIMISTIC ATTITUDES TOWARDS THE FUTURE 

17% OF INDIVIDUALS WITH SIGHT LOSS REPORT GETTING SUPPORT FROM CLINICAL OR REHABILITATION STAFF FOR EMOTIONAL PROBLEMS

PREDICTORS OF DEPRESSION



ADJUSTMENT TO SIGHT LOSS



STRESS



DISCRIMINATION



ISOLATION AND LONELINESS

RISK FACTORS PREDISPOSING PEOPLE TO SEVERE SIGHT LOSS 
AUTISM AND DEMENTIA

2.2 Mental Wellness and Balance

Mental Wellness and Balance Key Findings:

- People with Sight Loss exhibit lower levels of wellbeing and higher levels of mental health problems than those without Sight Loss.
- Sight Loss is associated learning disabilities, autism, depression and dementia.
- Mental health problems can result from neurological conditions particularly those leading to autism and dementia.
- Depression can be the result of trauma of adjusting to and living with severe visual impairments.
- People with severe Sight Loss report their wellbeing suffers from being discriminated against in public places and public services.
- Only 17% report getting help with emotional problems from health and social services
- Eye Clinic Liaison Officers (ECLOs) have responsibility for supporting people with Sight Loss in the NHS including emotional needs.
- A poor diet leads to a greater risk of all major eye diseases including glaucoma, diabetic retinopathy and age-related macular degeneration (AMD).
- People with severe Sight Loss have difficult maintaining a good diet because of mobility and access problems.
- People who smoke are twice as likely to develop AMD and are three times more likely to develop cataracts.

- There is no evidence that people with severe Sight Loss in the UK smoke more than the general population.
- Excessive consumption of alcohol and use of illicit drugs is associated with cataract development.
- No evidence of people with Sight Loss being heavy drinkers or drug users although some evidence of their use as coping strategies in the transition to severe Sight Loss.
- Services to support people with diet, smoking or drug problems are widely available but are difficult to access by people with severe Sight Loss.

Many people who have sight loss have lower levels of well-being than the general public and tend to exhibit mental health problems⁹⁰. It is reported that of the people attending low vision clinics, ranges from 22% and 38% that display symptoms of clinical depression⁹¹. An analysis of the GP records of 5,348 patients with visual impairment found that low vision was associated with eight mental health conditions, including depression, schizophrenia, dementia, anxiety and learning disabilities⁹². A systematic review of 29 studies found that working-age adults with visual impairment were significantly more likely to report lower levels of mental health, social functioning, and quality of life⁹³.

2.2.1 Mental Health

Four explanations have been advanced to explain the correlation between sight loss and mental health.

Underlying neurological conditions lead to sight loss and mental health problems. This explanation is proposed to account for the finding

that people with learning disabilities are ten times more likely to have sight loss problems than the general public in similar age bands^{94 95}. Cortical or Cerebral Visual Impairments (CVIs) can lead to vision loss and learning disabilities⁹⁶. The link between sight loss and many mental health conditions has also been researched. A literature review on autism and sight loss concluded there was a neurological basis for the strong correlation between the two conditions⁹⁷. A review of the Scottish census data for 2011 found a 17.5% overlap between reports of autism and reports of visual impairment and blindness. The authors draw attention to the difficulties of separately diagnosing the conditions when they are often part of complex needs, including deafness and learning disabilities⁹⁸. A study conducted by Aston University in Birmingham of children with Down Syndrome found that 38% also had suspected CVI (Cerebral Visual Impairments)⁹⁹. The conditions associated with underlying neurological conditions are those with onsets in childhood that have to be managed throughout life.

2.2.2 The Trauma of the Onset of Sight Loss

The RNIB estimates that 250 people each day in the UK will start to lose their sight¹⁰⁰. Receiving a severe sight loss diagnosis that is impossible to correct and adjusting to this life-changing event is a significant source of stress. A study of older people (average age 64) in Scotland found that the adjustments to impending blindness involved not only coping with the deterioration of sight but also with the socio-emotional traumas of experiencing loss, experiencing changed perceptions of self in relation to society, experiencing others in a changing way and experiencing rehabilitation. These adjustments were associated with lower levels of mental health, especially depression. The process of adjustment has been equated to a grieving process, in this case, the 'death' of the person as they were and adjustment to being a new person with sight loss¹⁰¹.

A systematic review of studies on the adjustment process concluded that it was characterised by various mental health issues, including depression, anxiety and fear, loneliness, isolation, reduced social functioning, and decreased quality of life¹⁰².

2.2.3 Dementia

There is a strong correlation between sight loss and a mental health condition without evidence of a common neurological condition. There is a strong correlation, for example, between dementia and sight loss as people get older. At least 1,048 people in Birmingham, mostly over 45, will have dementia and sight loss¹⁰³.

There is, however, evidence that some sight loss conditions may be associated with the onset of dementia, suggesting there may be an underlying systemic cause. An analysis of over one-million person-years of the lives of 2,304 people in the UK Biobank¹⁰⁴ longitudinal programme who developed dementia found a strong correlation with three sight loss conditions: age-related macular degeneration (AMD), cataracts and diabetes-related eye disease (DRED).

A review of the implications for the care of the elderly highlighted the high risk to the safety of the concurrence of the two diseases and found that care professionals prioritised the reduction of risk rather than seeking ways of preserving the independence of the older adult¹⁰⁵.

Up to 850,000 people in the UK have some form of dementia, and the prevalence of sight loss is higher among people with dementia, especially those living in care homes.

In Birmingham, it is estimated that 33,500 people live with dementia, and within this group, it is estimated that 5,600 people have dementia and significant sight loss.

2.2.4 The Emotional Cost of Living with Sight Loss

The RNIB estimate that one in five people in the UK will live with sight loss in their lifetime¹⁰⁶. Many studies have identified the challenges of living with a sight loss condition. Most studies have been on people who are blind or have very poor eyesight and who often become isolated in their own homes—a survey by the RNIB¹⁰⁷. Of 1,200 people living with severe sight loss, less than one in four working-age people are in employment, and difficulties in mobility and managing transport systems tended to curtail outside activities. Two-thirds of working-age people and one-third of pension-age people had collided with an obstacle on the pavement in the last three months. Working-age people reported experiencing considerable financial hardship: 40% reported having difficulty ‘making ends meet’. In the home, people with severe sight loss often need help with household tasks such as cooking, cleaning, setting heating controls, reading posts, dressing appropriately, etc. In a world increasingly dominated by digital services, they also had more difficulty than the general public managing new forms of technology.

As a result of these ongoing challenges, people with severe sight loss report low levels of well-being and 31% reported having pessimistic attitudes towards the future¹⁰⁸. Although there are many sources of paid and unpaid help with the many practical difficulties, the report found that only one in three registered blind people received mobility training and only one in five received practical support around the home. Only 17% of people with severe sight loss reported being offered emotional support.

People with severe sight loss also report being discriminated against. In a study of 7,677 older men and women in the English Longitudinal Study of Ageing¹⁰⁹, people with sight loss reported more incidents of discrimination by the public, by shops and other services and by healthcare staff than was written by people with normal sight. 52% of those with poor eyesight reported discrimination compared with 44% of people with good eyesight.

People with poor eyesight reported that discrimination had a negative effect on their wellbeing, contributing to loneliness, depression and lower levels of life satisfaction

2.2.5 Provision of Support

The RNIB survey of 1,200 people with sight loss found that only 17% reported being offered any emotional support¹¹⁰. Despite many different types of support being available to support people with sight loss and mental health conditions. When people with severe sight loss are diagnosed with specific mental illnesses such as autism, schizophrenia or learning disabilities, there are specialist health service treatments to which they can be referred. However, in each case, the treatment may place emphasis on the mental health condition rather than the sight loss.

Other approaches do focus on the two conditions together. Studies have been undertaken, for example, to explore the efficacy of treatments for the depression experienced by people with severe visual impairment. In a randomised control trial¹¹¹, patients attending low sight clinics were assigned to one of three conditions: 1) a control group, 2) a group referred to their doctor to work through a NICE recommended approach to reduce the symptoms of depression and 3) a referral to a therapist to administer PST, a seven-step problem-solving approach to help people manage the specific problems of their sight loss. In the results, both the NICE and PST approaches led to a greater reduction in the symptoms of depression than the control, with the PST treatment obtaining significantly better results than the NICE approach. However, the authors caution that the improvements were not dramatic.

Within each local authority in England, two services have been established to make early assessments of the needs of people newly diagnosed with severe sight loss, including the required emotional support. Eye Clinic Liaison Officers (ECLOs)¹¹² who provide sight loss advice services are within

eye clinics or hospitals. Their role is to help patients recently diagnosed with an eye condition or experiencing changes in their eyesight to understand the impact of their diagnosis and provide patients with emotional and practical support.

Within local authorities, the rehabilitation service includes Visual Rehabilitation Officers¹¹³, whose function is to provide people with severe sight loss with help with a wide range of issues from medication and the provision of ophthalmic aids to emotional support and guidance on entitlements. All Local Authorities in England are required by the Care Act 2014 to provide this service, but the RNIB reports that the service is limited in many parts of the country because of budget cuts to social care. In a survey of 270 people with sight loss, a third of respondents reported that they have had no contact with their local authority, and 49 per cent of people who were in contact with their local authority did not go on to receive an assessment for vision rehabilitation support¹¹⁴.



Where support is provided, existing evidence suggests it directly impacts the management of sight loss but less impacts wider issues of mobility, independence, and emotional health. An exploratory randomised trial¹¹⁵. Compared outcomes for 35 people with sight loss who received visits from a Visual Rehabilitation Officer with 32 people who did not. The results showed that the people receiving visits improved the management of their visual function compared to the control group. Still, there were no statistical differences in measures of emotional wellbeing.

A study of the Visual Rehabilitation Service in Surrey¹¹⁶ examined the impact of home visits by the service on 702 people newly diagnosed with sight loss. The assessment concluded that for every £1 invested, there was a return of £1.30 because of direct savings resulting from more functional independence and fewer falls and indirect savings through improved mental health.

In Birmingham,¹¹⁷ support for people newly diagnosed with a severe eye condition is provided by the Visual Impairment Service and the Eye Clinic Liaison Officers (ECLOs). Services for adults with a visual impairment are provided by the Birmingham City Council Visual Impairment Service, which has a social work team and a rehabilitation team.

The ECLOs are based within eye clinics or hospitals. Their role is to help patients recently diagnosed with an eye condition understand the impact of their diagnosis and provide patients with emotional and practical support. ECLO support is not available in every NHS Trust or Health Board. The RNIB¹¹⁸ reports that in Birmingham and the Black Country, 3 NHS Trusts had access to an Eye Clinic Liaison Officer out of 6 Trusts.

Birmingham also has an 'Improving Access to Psychological Therapies' (IAPT) service¹¹⁹ delivered by Birmingham and Solihull Mental Health NHS Foundation Trust and is known as Birmingham Healthy Minds. The service can be accessed through self-referral or a GP. The service offers advice,

information and brief psychological talking therapies for people aged 16 and over who often feel anxious, low in mood or depressed.

There is no data about the degree to which people with visual impairment in Birmingham access these services.

2.2.6 Alcohol and Substance Abuse

A complex relationship exists between sight loss and the lifestyle led by people at risk of having a visual impairment. There is evidence that some lifestyles put people at risk of visual impairment, and in some cases, lifestyles are associated with specific visual impairments. There is also some evidence that having a visual impairment makes it more likely that people will adopt a lifestyle that puts them at risk of further deterioration of their visual functions.

2.2.7 Smoking

People who are current smokers are twice as likely to develop age-related macular degeneration (AMD) as non-smokers of a similar age. A review of 17 studies¹²⁰ 13 found evidence that current smokers had a two-fold or three-fold risk of developing AMD. A major survey¹²¹ of people over 75 in 49 UK GP practices found that current smokers were twice as likely as a control group to have AMD. The association was much weaker if people had stopped smoking 10 years ago and was non-existent if they had stopped smoking 20 years ago. The authors estimate that there are 28,000 cases of AMD in the UK that could be attributed to smoking. People who smoke are three times more likely to develop cataracts than comparable age groups¹²².

Although there is no evidence that people with sight loss smoke more than the rest of the population of comparable age, there is some evidence from the USA that people with sight loss do smoke more¹²³.

2.2.8 Alcohol and Substance Abuse

Excessive alcohol consumption and illicit drugs can have a very damaging effect on ocular functions. A meta-analysis of studies of the relationship between alcohol consumption and the development of cataracts, for example, concluded that heavy drinking, defined as 20g per day or more, was associated with cataract development but that there was no association with more moderate drinking¹²⁴.

There is very little evidence that people with severe visual impairments in the UK drink alcohol excessively or have an illicit drug habit. There is some evidence that in the process of adjusting to a major loss of visual functioning, some people may resort to alcohol or drugs as coping mechanisms. A qualitative study¹²⁵ of users' perspectives on substance use found that people with severe visual impairment thought that alcohol led to their sight loss or contributed to it. That substance use helped them to cope with the consequences of sight loss. A qualitative study of 30 male¹²⁶ and 9 female¹²⁷ service personnel who had sustained a vision impairment found that some personnel used alcohol and drugs as a coping mechanism when adequate support to adjust to a new lifestyle was absent.

2.2.9 Domestic Abuse/Violence

No statistics are available that detail how people with severe sight loss are subjected to abuse either in the home or when in public places. However, the RNIB¹²⁸ reports many cases where people with severe sight loss have been abused by partners upon whom they depend for care and others who have been assaulted or robbed whilst travelling. People with severe sight loss report feeling vulnerable and defenceless in many circumstances.



2.3 Healthy and Affordable Food

2.3.1 Diet

A poor diet has been identified as a risk factor in both the onset and subsequent management of several major visual impairment causes in the UK. A systematic review of the impact of visual impairment on nutritional status¹²⁹ concluded that people in the UK with severe visual impairments tended to be obese, i.e., to have an abnormal BMI index over 30. Still, there were also reported cases of malnutrition. A strong correlation has also been found between type II diabetes and poor diet, and people with diabetes are likely to develop diabetic retinopathy.

A poor diet is a risk factor concerning all major causes of visual impairment in the UK: age-related macular degeneration, diabetic retinopathy, cataract and glaucoma. A review of dietary factors¹³⁰ concluded that the risk might be decreased by a diet that increases the intake of green leafy vegetables and reduces the glycaemic index by, for example, increasing the intake of fish that contain Omega-3 fatty acids. Vitamin supplements can also reduce the risk.

People with severe visual impairments face many challenges that make it difficult to sustain a healthy diet. Mobility problems may make shopping difficult and preparing and cooking food may be additional burdens¹³¹.

2.3.2 Services to Support Healthy Lifestyles

The Birmingham and Solihull Health and Sight Loss Evidence Base¹³² lists the services that help people improve their diet, stop smoking and reduce dependence on alcohol and drug consumption. However, it is noted that none of these services has specific provisions for people with severe visual impairments, and it is doubtful they would find them accessible. A review that demonstrates that the provision of support to develop healthy

lifestyles is a problem across the developed world lists possible strategies for intervention: building modules on, for example, healthy diets, into rehabilitation sessions, convening local groups of people with visual impairment to share problems and solutions for healthy living and providing accessible information using modern technology¹³³.



RESULTS OF SEVERE SIGHT LOSS



FALLS DUE TO SIGHT LOSS

THE NIB ESTIMATES THAT IN BIRMINGHAM,

3,270

people with sight loss over 65 experience a fall per year



1,550 OF THESE FALLS, ARE DIRECTLY ATTRIBUTABLE TO SIGHT LOSS

PHYSICAL ACTIVITY

64% OF PEOPLE WITH SIGHT LOSS IN A UK SURVEY WOULD LIKE TO DO MORE EXERCISE

Low levels of physical activity can result in higher obesity, glaucoma, AMD, diabetes and Retinopathy



2.4 Active at Every Age and Ability

Active at Every Age and Ability Key Findings:

- People with severe Sight Loss partake in much less physical exercise than others of comparable ages.
- Mobility problems prevent many people with Sight Loss from engaging in physical activity.
- Many people with sight loss would value participation in sport but there are few opportunities that are accessible to them.
- Poor physical fitness can lead to the development of glaucoma, age-related macular degeneration and diabetic retinopathy.
- Physical exercise can slow down the further development of eye diseases that have already been diagnosed.
- Very little institutional support is available to help people take physical exercise or engage in sporting pastimes.

2.4.1 Physical Exercise

People with severe sight loss are likely to lead a more sedentary life than others. People who are blind or have low vision in all age bands are much less physically active than the rest of the population¹³⁴. In the RNIB My Voice survey of 1,200 people, 64% said they would like to do more physical activity. This was true of people of all ages. 60% of people aged 75 and over said that they would like to do more physical activity¹³⁵. However, there are many challenges people with severe sight loss face in taking physical exercise away from their homes. A survey of 60 people over 60 years of age with severe sight loss¹³⁶ identified six reasons for low levels of physical activity: environments that were disabling, e.g. gyms with inaccessible

equipment; a lack of organisational opportunities, e.g. appropriate clubs to join; problems with transport, lack of information to know what was possible, confidence, e.g. fear for personal safety and a lack of opportunity to use physical activity as 'medicine' for a related condition. Other studies have confirmed these challenges.

There are few sports that a person with severe sight loss can take part in alongside sighted people. Special forms of sporting activities and events need to be organised in which people with similar disabilities can engage, as in the sight-impaired competitions in the Paralympics¹³⁷. Children have opportunities to engage in organised sport whilst at school. Still, even when engaged in similar activities, children with poor sight did so with a lower activity level than sighted children, and girls did so less energetically than boys¹³⁸.



2.4.2 Mobility and Transport

To exercise outdoors or visit sports and recreational venues, people with poor sight have to venture into public streets, engage with public transport, or use cars driven by sighted people. Although mobility training is widely available, less than one in three receive help in the first year after sight loss. The RNIB My Voice survey of 1,200 blind or partially sighted people found that those who received training were age-related: older people were much less likely to be offered mobility training than those of working age¹³⁹. Walking can be difficult because there are many street furniture and traffic hazards to negotiate for a person on foot with sight loss. In the RNIB My Voice Survey¹⁴⁰, 40% of respondents could not make all the journeys they wanted or needed to make, and around half required support to get out of the house. Two-thirds of working-age people and one-third of pension-age people 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. People identified the most common barriers were street furniture, parked cars, advertising boards, and wheelie bins.

There are also many challenges in using public transport, including knowing which bus to board, knowing when the exit stop has been reached, boarding a bus and exiting into a busy thoroughfare¹⁴¹. For people with severe sight loss who have access to cars, blue badges enable parking close to destinations. People registered as blind are automatically entitled to a blue badge if they register for one.

In Birmingham, 316 blue badges were issued to people with sight loss in 2015/16. 828 blue badges were held by people registered blind in 2016, which represents 21% of people who are registered blind¹⁴².

2.4.3 Sensory Coordination and Falls

Many people with severe sight loss do not have the confidence to venture out to engage in physical exercise because they fear they may be involved in an accident or may have a fall. A survey of the hospital records in the UK in 1999 found that of the 2.35 million recorded falls, 189,000 (8%) occurred to people with a visual impairment, of which 89,500 were attributed to the visual impairment itself¹⁴³.

The RNIB estimates that in Birmingham, 3,270 people with sight loss over 65 experience a fall per year and that, of these falls, 1,550 are directly attributable to sight loss. 260 people over 65 with sight loss experience a severe fall per year that results in hospital admission through A&E. Of these severe falls, 120 are directly attributable to sight loss¹⁴⁴.

People with little or no sight have lower coordination and balance levels than the sighted. Physical exercises involving perceptual motor skills can be difficult and potentially dangerous¹⁴⁵. It is one of the key reasons people with severe sight loss are likely to do so with less vigour than sighted people, even when taking physical exercise.

People with severe sight loss often have other serious health issues, and the combination of conditions may make taking physical exercise difficult. The other conditions associated with severe sight loss include learning disabilities, autism, dementia, diabetes, and hearing loss¹⁴⁶.

Engaging in regular physical exercise in their own homes may be an option for people with severe sight loss. Still, many, especially in deprived areas, do not have the facilities for it, and when it is introduced, it may not be sustained¹⁴⁷.

One of the reasons people with severe sight loss give for not being able to take regular physical exercise is that they need help, particularly with walking and transport. Ideally, the help would be from a sighted person. However, in the RNIB My Voice survey of 1,200 people with severe visual impairments, 19% of respondents reported a lack of sighted help or assistance with transport¹⁴⁸.

People with severe sight loss express a strong desire to be as independent as possible. There are many aids and services designed to enable them to be independent in walking, travelling, and physical exercise. These include the traditional white canes, guide dogs and, more recently, technology aids that, for example, use GPS to identify the location of the person and download map information to braille readers¹⁴⁹. Although there are no available statistics on the use of these aids by people with severe sight loss, it is probable that the percentage of people who access these services is quite low. People would need to know of these aids and services and then be able to locate them, and it can be difficult for people with recent severe sight loss to access support services. The RNIB report that 49% of people in contact with their local authority do not go on to receive an assessment for vision rehabilitation support¹⁵⁰.

There are estimated to be 4,800 working guide dogs in England, serving an estimated population of 245,000 blind people, and there are long waiting lists¹⁵¹.

Although digital technology aids are increasingly sophisticated and available, people with severe sight loss are less able to use them than sighted people. The RNIB My Voice survey¹⁵² found that 82% of younger people aged 18-29 with sight loss were making wide-ranging use of digital technology compared with 25% of people over 75 years old. However, it is estimated that 96% of the younger age group who are sighted now make regular use of digital technology. In the survey, respondents reported that sight loss remained a barrier to using digital technology to support travel and physical exercise. Although there were many aids to help people with sight loss make use of the technology, they were more usable in the home and in employment than whilst travelling.

60% PUPILS WITH SIGHT LOSS
HAVE OTHER SPECIAL
EDUCATIONAL NEEDS

3,170 STUDENTS WITH SEVERE
SIGHT LOSS IN HIGHER
EDUCATION (2017/18)

BARRIERS TO HIGHER EDUCATION



FINDING
SUPPORTIVE
INSTITUTIONS



STUDYING
THE SUBJECT



MOBILITY ON
CAMPUS



INDEPENDENT
LIVING

33% OF WORKING AGE ADULTS
WITH SEVERE SIGHT LOSS
ARE IN EMPLOYMENT



ALMOST HALF OF PEOPLE WITH SIGHT
LOSS IN BIRMINAHAM
HAVE A WEEKLY
INCOME OF **£300**

2.5 Working and Learning Well

Working and Learning Well Key Findings:

- At both primary and secondary school levels pupils with Sight Loss have lower levels of attainment than sighted pupils.
- In 2017/18 3170 students with severe Sight Loss were registered in UK universities.
- Only 1 in 4 people with severe Sight Loss problems who are of working age are in employment.
- 1 in 5 with severe Sight Loss struggle financially. It rises to 33% of those of working age who are not eligible for a pension.
- Extra costs of living associated with Sight Loss (mobility help, domestic help etc.) add to financial struggles
- In Birmingham in 2020, 1,724 blind and partially Sight Loss claimed PIP (Personal Independence Payment) or DLA (Disabled Living Allowance).
- Some communities are more vulnerable to financial pressures: those with other serious health problems, in deprived areas or in Black and minority ethnic communities.
- People from Black and ethnic minority communities are more susceptible to some eye diseases, e.g. Black African and Caribbean people are 4-8 times more at risk of developing glaucoma. Asian people are more likely to develop cataracts and South Asian people are 3 times more likely to develop diabetic eye disease.

2.5.1 Education

The RNIB My Voice survey of 1,200 people with severe sight loss found that 27% had a degree or higher-level qualification, while 33% reported no qualifications. Older participants were more likely to have no qualifications than younger people. 38% of people of pension age reported having no qualifications compared to 9% of people under 50 years¹⁵³. Given that the onset of slight loss may be at any stage of life, most qualifications may be gained before people suffer sight loss. However, the question of how people who have sight loss cope in the education system will be significant for many people and is addressed below.

At both primary school and secondary school levels, pupils with visual impairments record lower levels of achievement than their sighted counterparts. However, 50% of pupils with visual impairment also have other special educational needs. An analysis for the RNIB¹⁵⁴ of the National Pupil Datasets for 2008/09 held by the Department of Education examined the performance of sighted pupils, pupils with only a visual impairment and pupils with a visual impairment and other special educational needs. At all stages of primary education, the sighted pupils did best, followed by those with only a visual impairment and those with another particular educational need. These gaps widened with every year of education. This pattern was repeated at the age of 16 when pupils undertook GCSE examinations

There are no comparable studies of attainment levels in higher education. However, there is evidence that the challenges of studying in universities and colleges mean that visually impaired and blind students represent a relatively small percentage of the total number of students. An analysis of Higher Education Statistics Agency data for 2017/2018¹⁵⁵ found 3,170 students registered and identified as visually impaired across all levels of study. A number of studies^{156 157} have followed the progress of students with severe visual impairments and have identified the following challenges:

Getting support to study

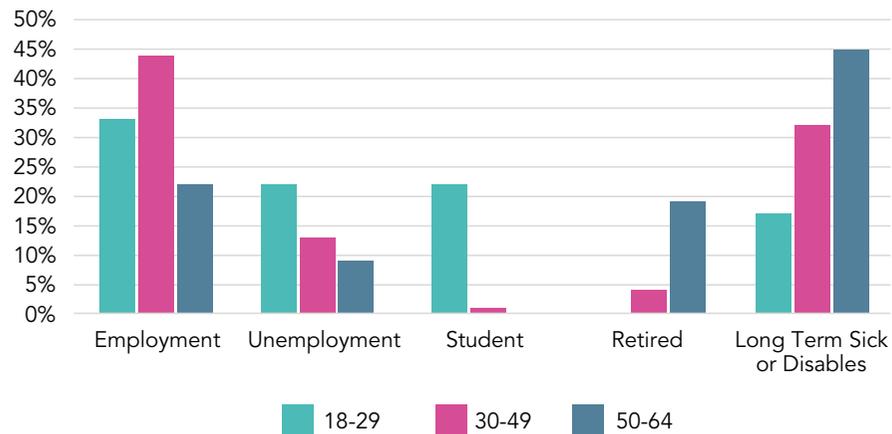
Universities and colleges are required under the UK Equality Act 2010 to make reasonable adjustments for students with special needs, including those with sight loss. Many now have provisions including special computer equipment, help with notetaking, special arrangements for examinations, and extra time. Each student has unique needs, and most universities and colleges have a disablement officer to help organise appropriate assistance. Despite this progress, most studies find that assistance is patchy and that students struggle to maintain the progress made by sighted colleagues.

Living independently away from home

Most students move to live on or near a university campus to study, which means they have the challenge of living independently, usually for the first time. The studies have found that students are often not well prepared for this new life. A common recommendation is that in transitioning from secondary school to higher education, in addition to their academic studies, pupils should have detailed training in living independently.

2.5.2 Employment and Financial Well-being

Estimates of the employment rate of people with severe sight loss who are of working age vary from 25%¹⁵⁸ to 33%¹⁵⁹. All studies agree that the employment rate is significantly below the UK rate for the general population of 4% (8% in Birmingham)¹⁶⁰. A study of 1,000 people in England with severe sight loss aged between 18 and 64 provided the following statistics on employment rates and other outcomes as shown by figure 5 (see Appendix 6 for full data)¹⁶¹.

Figure 5: The Employment Status of People with Visual Impairment

Source: Douglas et al., 2009

44% of respondents in the main working-age band (30 to 49 years) were employed. 33% of younger people (18 to 29 years) were employed whilst 22% were students. In the older age range (49 to 64 years), 22% were in employment, and 19% declared themselves retired, although they had not reached the age to receive the state pension. However, 33% of all respondents reported they were long term sick or disabled, and 45% of the older age band placed themselves in this category. A small percentage of the study cited their employment status as 'looking after family or home' or 'something else'.

Several studies have explored the barriers that prevent more people with severe sight loss from obtaining employment. A survey of 559 people with severe sight loss who were of working age concluded that the factors that influenced employment prospects were educational attainment, housing tenure, registration status (as blind or visually impaired) and

having additional disabilities¹⁶². A survey of youths with visual impairment transitioning from education to employment added two other factors: the person's confidence in undertaking the work required and their competence with assistive technology that would enable them to perform tasks alongside sighted colleagues. Assistive technology includes traditional reading aids such as Braille and mobility aids such as white canes. However, as most jobs now involve working with computers, assistive technology that enables people with visual impairments to undertake computer work is particularly important. It includes magnifiers for use by people with low vision, tactile keyboards and products that convert text to synthesised speech. The transition from education to employment is more accessible if the person with vision loss has developed competence with these aids during their education¹⁶³.

The RNIB 'My Voice' survey of 1,200 people found that one in five blind and partially sighted people reported they have 'some or great difficulty in making ends meet'. This was most 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. The 39–49-year-old group were the people who struggled to find employment, and many of the older group had 'retired' prematurely before reaching the age when they could receive the state pension. Nearly half of working-age people reported they could not afford to pay for a week's holiday away from home or a necessary but unexpected expense of £500¹⁶⁴. The England Vision Strategy¹⁶⁵ reports that 49% of people with sight loss in Birmingham live in a household where the weekly income is less than £300, and people with sight loss are twice as likely as those with no impairment to have a weekly household income of less than £300.

Many of the people in this survey were eligible for disability benefits (Disability Living Allowance (DLA) and Personal Independence Payment (PIP)), but more than one-quarter of all ages said that the disability benefits they received were rarely or never enough to enable them to cope

financially. Having a severe sight loss condition means people encounter extra costs to average household expenditure. These include the cost of technological aids, additional costs for transport and the costs of domestic support and modifications to homes¹⁶⁶. In the 'My voice' survey¹⁶⁷, people reported that the disability benefit designed to meet these extra costs was rarely sufficient for the purpose.

The majority of blind and partially sighted people need help around the house. This support ranges from tasks like preparing meals or personal care to help with setting heating controls or help with selecting clothing. In the survey, nearly half of the blind and partially sighted people said 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 unpaid and was provided by the spouse or partner and, depending on the person's age, either children or parents. People outside the home who provided care were typically paid support workers or friends and neighbours.

In Birmingham, in 2020, there were 1,724 blind and partially sighted people claiming either Personal Independence Payment (PIP) or Disabled Living Allowance (DLA). In May 2020, 1% of working-age DLA claimants were waiting to be moved on to PIP¹⁶⁸.

The RNIB reports^{169, 170} that some parts of the sight loss community are more exposed to financial hardship and problems accessing education and employment than others. Age, additional disabilities, severity of sight loss and educational attainment level are all factors that influence the employment status of blind and partially sighted people.

2.5.3 Housing

People with severe sight loss need a home environment where they can move around safely and confidently. They also need facilities in kitchens, bathrooms, etc., to accomplish domestic tasks safely. Many studies have led directly to the development of guides that provide practical advice for managing sight loss in homes. Working with 360 people who had both sight loss and dementia or who cared for them, a team at Stirling University¹⁷¹ has developed a guide that, amongst other advice, provides guidance on the re-design of the interior of homes, for example, to give people safe and familiar routes to follow, important aids for both sight loss and dementia. The hope is that the greater confidence this instils will help sustain self-management and contribute to the well-being of people with both conditions.

2.5.4 Long-standing health impairment, illness or disability

People with learning disabilities and/or autism are 10 times more likely to experience sight loss than the general population. In Birmingham, it is estimated that 1,250 adults have a learning disability and partial sight. A further 360 adults have a learning disability and blindness.

The 2019/20 register of blind and partially sighted people also record learning disability. In Birmingham, people 155 are registered blind and partially sighted and with a learning disability.

1 IN 40 GP CONSULTATIONS ARE CONCERNING EYESIGHT

PREVENTABLE SIGHT LOSS 50%

OF BLINDNESS AND SEVERE SIGHT LOSS CASES COULD BE PREVENTED IF DETECTED AND TREATED IN TIME BY REGULAR TESTING

397,835

ANNUAL OUTPATIENT CONSULTATIONS IN BIRMINGHAM TREATING EYESIGHT PROBLEMS

41,965

ANNUAL INPATIENT PROCEDURES IN BIRMINGHAM TREATING EYESIGHT PROBLEMS

BARRIERS TO EYE TESTING

Reported reasons for individuals not attending eye tests



LANGUAGE BARRIERS



PERCEIVED COST OF OPTOMETRISTS AND RETAIL ELEMENT ASSOCIATED WITH VISITING OPTOMETRISTS



ONLY TEST WHEN SHOWING SYMPTOMS



EYESIGHT TESTING NOT SEEN AS REGULAR HEALTH ISSUE

UPTAKE OF EYE TESTING

Communities with the lowest levels of eyesight testing include

PEOPLE WITH LEARNING DISABILITIES AND AUTISM, OLDER ADULTS, ETHNIC MINORITY COMMUNITIES, INDIVIDUALS FROM AREAS OF HIGH DEPRIVATION, WORKING-AGED MALES



2.6 Protect and Detect

Protect and Detect Key Findings:

- 50% of eyesight problems could be prevented or treated by early detection.
- Eyesight screening tests are recommended every two years throughout life, but approximately half of the UK population do not undertake tests every two years.
- Screening for diabetic retinopathy achieved 82.8% take-up in 2015-16.
- Communities with low eyesight screening uptake include: people with learning disabilities and autism, older people with dementia, Black and ethnic minority communities and people from deprived areas.
- Reasons for not taking eyesight screening tests include: lack of awareness that eye health is important, only attending when there are symptoms of eye problems, transport and mobility issues, worry of associated costs.
- People with severe Sight Loss find navigating the referral process for treatment challenging and may have mobility issues when attending.
- Practice procedures and information presentation can challenge people attending GP practices with eyesight problems.
- COVID-19 has had a major impact on people with sight loss; they are lonelier and more isolated, have greater mobility difficulties, and fear that delays in treatment may mean their eye problems further deteriorate.

2.6.1 Eyesight Screening

Screening for eyesight problems is essential if corrective measures are put in place. Eyesight problems can occur at any stage of life and are particularly prevalent in older age groups. Regular eye checks are necessary throughout life, and the recommendation is that eye checks are made at least every two years¹⁷².

The RNIB estimates that 50% of blindness and severe sight loss cases could be prevented^{173 174} if detected and treated in time. This is mainly due to uncorrected refractive error and untreated cataracts. Low take-up of sight tests can lead to detection after the condition has deteriorated, and intervention may be less effective.

Prevention of avoidable sight loss is recognised as a key priority for the WHO's global initiative to eliminate avoidable blindness by 2020 – Vision 2020 – The Right to Sight¹⁷⁵, to which the UK is a signatory and is also a key priority for Vision UK.

The Availability and Take-Up of Eyesight Tests

Free NHS sight tests are available to people in England who meet certain criteria. For example, people aged 60 or over, children aged 15 and under, and people receiving certain benefits. Public data on sight tests only records those paid for by the NHS. Data about privately funded sight tests are not available.

The RNIB reports that 12,995,512 NHS eyesight tests were conducted in England in 2016/17, of which 697,504 were in Birmingham and the Black Country area^{176 177}. In Birmingham, in terms of the groups eligible for NHS sight tests:

- 244,524 sight tests were taken by people aged 60 years and over
- 183,179 sight tests were taken by children aged 0 -15

- 31,909 sight tests were taken by students aged 16-18
- Benefit claimants took 115,769 sight tests.

In Birmingham, the School Entry Vision Screening Service undertakes an eye test for every child's reception year¹⁷⁸. It is offered in every primary school in Birmingham, including special schools and religious schools.

There is also a specialist diabetic retinopathy screening service. The English NHS Diabetic Eye Screening Programme¹⁷⁹ aims to reduce the risk of sight loss amongst people with diabetes or sight-threatening diabetic retinopathy. In England, screening is offered annually to all people with diabetes aged 12 years and over. The uptake of the programme in 2015–16 was 82.8% when 2.59 million people with diabetes were offered screening, and 2.14 million were screened. The benefit of the programme is that, in England, diabetic retinopathy/maculopathy is no longer the leading cause of certifiable blindness in people of working age. However, the English Vision Strategy¹⁸⁰ reports that in 2012/13, the proportion of patients invited to attend a retinopathy screening in Birmingham was 74.2%, compared with 79.1% in England. Further, the rate of confirmed diabetic retinopathy in Birmingham in 2018 was 4.1 per 100,000 compared with 3.2 for England.

For other members of the population, eyesight tests are widely available. The English Vision Strategy¹⁸¹ estimates that 166 optometrists, mostly in high street locations in Birmingham, offer a full range of eyesight tests.

Communities at Risk of Infrequent Eyesight Tests

Some communities have been identified as having relatively low regular attendance rates for eyesight tests¹⁸². They include the communities or groups that have also been identified as being most at risk of developing an eye disease or of having sight loss alongside other chronic health conditions:

- People with autism and learning disabilities
- Older people, particularly those with dementia and with mobility problems
- Working-age males
- People from areas of multiple deprivations
- Black and ethnic minority communities

A study¹⁸³ that explored the reasons for not attending regular eyesight tests in five UK communities with large ethnic communities and/or high levels of deprivation focused on exploring issues concerning specific eye conditions in each community. The study included 34 focus groups (289 participants), 56 case study interviews with members of the target populations and 55 interviews with eyesight test providers

The five local communities were:

- Bradford (diabetic retinopathy in a Pakistani population experiencing deprivation, aged 40 to 65)
- Cwm Taf (glaucoma in a white, deprived population, aged 40 years and above)
- Glasgow (diabetic retinopathy in Pakistani people living in affluent and deprived areas aged 40 to 65)
- Hackney (glaucoma in a Caribbean population, aged 40 to 65)
- West Belfast (glaucoma in a white, disadvantaged population, aged 40 to 65).

The reasons given in all communities for not attending regular eyesight tests included:

1. Limited community awareness of eye health - Eyesight was not regarded as a health issue requiring regular assessment.
2. Symptom-led demand for eye examinations - People only went for an eyesight test when they became aware that their eyesight was deteriorating.
3. The cost and retail element associated with primary care - Most opticians were located in the high street, often within large retail chains, and people associated them with selling expensive spectacles. They were more inclined to view independent opticians as professional health specialists, whereas opticians in large chains were regarded more as sales agents.
4. Community-specific reasons - The language was a barrier to accessing eye health services for some people in Glasgow. Physical access was an issue in Cwm Taf, reflecting the particular geography and relatively poor transport links of the Welsh Valleys.

Consultations on Eye Health

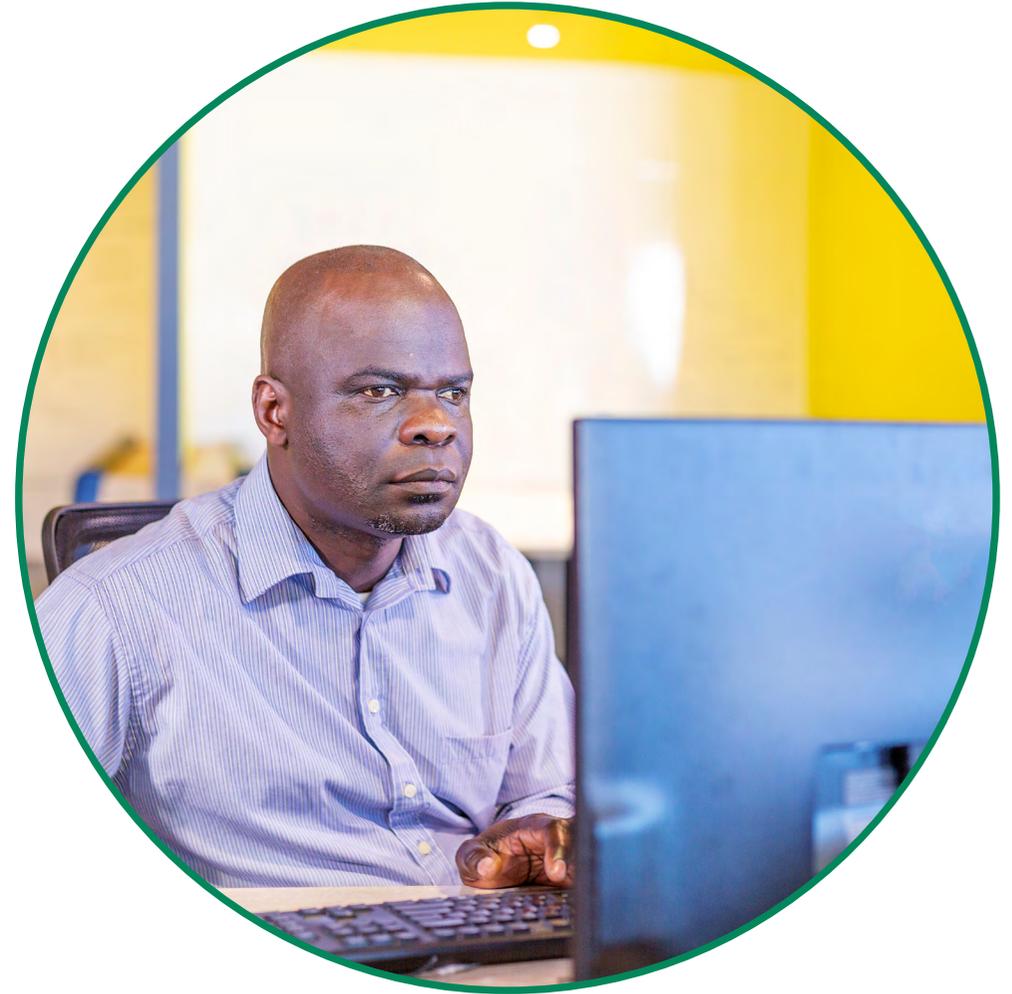
In 2013, visual health was made a clinical priority for GP practices. The England Vision Strategy¹⁸⁴ estimates that in 2018, there were 4.5 million GP consultations in England that concerned visual health (approximately 1 in 40 of all consultations). The consultations may be for patients reporting early symptoms of eye problems or who already have severe sight loss and need access to rehabilitation and other services. NHS England (West Midlands)¹⁸⁵ conducted an audit of 18 GP practices in the city to establish the accessibility of the practices to patients with eye health concerns.

The audit identified five barriers:

- Physical barriers – mobility issues making travel to the practice difficult
- Communication barriers – inability to read and understand practice notices and calling systems
- Procedural barriers – difficulties with paperwork and computerised check-in systems
- Medical obstacles – failure to recognise visual signs of illness
- Behavioural barriers – practice staff lack of awareness of the support needs of people with sight loss

2.6.2 The Impact of COVID-19 on People with Sight Loss

People with severe sight loss have a high incidence of isolation and loneliness, and Covid-19 has exacerbated this problem. A survey¹⁸⁶ of 325 people with severe sight loss found that the lockdown periods increased loneliness, negatively affected mental health, and further inhibited social life. A survey of 455 people with severe sight loss by the RNIB¹⁸⁷ found that the Covid pandemic also posed many practical problems, such as accessing the current Covid regulations and maintaining social distance. Respondents found it more challenging to shop for food because of the many new rules, procedures and screens protecting staff. There was also evidence that delays were occurring in appointments for hospital visits and respondents feared that delays in reviews and treatments would mean their eye conditions would further deteriorate. When people did attend clinical appointments, they found it even more difficult than usual to find their way and abide by all the requirements. A particular concern has been the barriers the people with severe sight loss may experience in attending centres for Covid vaccinations.

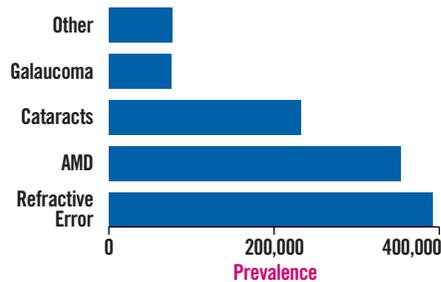


13% OF BIRMINGHAM POPULATION ARE AGED 65 AND OVER

70% OF THOSE WHO ARE BLIND OR PARTIALLY SIGHTED ARE OVER THE AGE OF 65



EYE DISEASE IN THE 65 AND OVER POPULATION IN ENGLAND IN 2013



LEADING CAUSE OF SEVERE SIGHT LOSS



60% OF THOSE AGED 65 AND OVER DEVELOPED SEVERE SIGHT LOSS AFTER A STROKE

2.7 Ageing Well and Dying Well

Ageing and Dying Well Key Findings:

- In the UK in 2019/20 69.9% of people with severe Sight Loss were aged 65 or over.
- In Birmingham in 2019/20 69.8% of people with severe sight loss were aged 65 or over.
- Sight Loss increases with age. 1 in 8 people over 60 have Sight Loss, this rises to 1 in 2 in those aged over 90.
- The leading causes of sight loss in older people are refractive errors, AMD (age-related macular degeneration), cataracts, glaucoma and diabetic retinopathy.
- There are nearly double the number of females over 65 with Sight Loss compared with males.
- Older people with Sight Loss frequently also have other major health conditions such as hearing loss, dementia, strokes, learning disabilities, diabetes, physical disabilities and poor mental health.
- Older people with Sight Loss have a high incidence of falls leading to hospitalisation.
- There are no agreed statistics on the life expectancy of older people with sight loss but hazard ratios range from 1:1.29 for mild Sight Loss to 1:89 for severe Sight Loss.
- The reduced life expectancy of people with Sight Loss is mostly attributable to the life expectancy of associated health conditions.

Five eye diseases account for most of the sight loss among the 65s. Deloitte Access Economics¹⁸⁸ analysed the incidence of sight loss for these diseases in England in 2013.

Table 6A: Sight Loss and Blindness in Older Men by Eye Disease in England (2013)

Age	AMD	Cataract	Diabetic Retinopathy	Glaucoma	R E	Other	Total
65-75	20,108	11,644	13,002	13,547	69,614	10,891	147,026
76-85	43,460	27,224	9,321	16,202	53,828	11,899	160,639
85+	52,368	35,623	636	9,222	34,421	10,573	142,743
Total	115,936	74,491	22,959	38,971	157,863	33,363	450,408

Table 6B: Sight Loss and Blindness in Older Women by Eye Disease in England (2013)

Age	AMD	Cataract	Diabetic Retinopathy	Glaucoma	R E	Other	Total
65 -75	22,363	36,820	7,920	11,778	75,822	12,376	167,077
75 -85	76,710	59,816	4,238	16,801	103,561	20,890	282,014
85+	156,092	87,778	4,121	24,654	71,259	27,512	371,407
Total	255,165	184,414	16,279	53,433	250,642	60,778	840,498

Table 6C: Total Sight Loss and Blindness in Older People by Eye Disease in England (2013)

Age	AMD	Cataract	Diabetic Retinopathy	Glaucoma	R E	Other	Total
Total >65	371,101	258,905	39,238	92,404	408,505	94,143	1,390,906
Total All	375,747	303,156	75,951	117,204	630,041	120,168	1,622,266
% > 65	98.76	85.40	51.66	78.84	64.84	78.34	85.74

Key: AMD = Age-related Macular Degeneration; RE = Refractive Error

Source: Deloitte Access Economics¹⁸⁹

- There were nearly double the number of sight loss cases for females compared with males, and this was true for all forms of eye disease except diabetic retinopathy.
- The greatest number of eye problems are refractive errors. This is the most frequent eye problem for all ages but the over 65s account for 65% of these problems.
- The next most frequent problem for the over 65s is AMD (Age-related Macular Degeneration). There were 371,101 cases in 2013, 99% of all cases. It is a disease that becomes more prevalent with age: there were 208,460 cases in the 80s compared with 42,471 for people in the 65 to 74 age group.
- Cataracts are also a disease of the elderly. In England, in 2013, there were over 300,000 cases in the 65 and over age bands (85% of all cases). In Birmingham, the estimated number living with cataracts is 8,740.
- The number of cases for all other diseases was less than 100,000.

2.7.1 Diabetes

Half of all people with diabetes in the United Kingdom are over 65 years and a quarter are over 75. People with diabetes are at risk of developing diabetic retinopathy, one of the leading causes of blindness. In Birmingham in 2019/20¹⁹⁰, it is estimated that:

- 62,100 adults have been diagnosed with diabetes.
- 21,800 people are living with diabetic retinopathy.
- Of these, 2,010 have severe diabetic retinopathy, a later stage of the disease that is likely to result in significant and potentially certifiable sight loss.
- In Birmingham¹⁹¹, it is estimated that 62,100 adults have been diagnosed with diabetes, and of these people, 21,800 live with diabetic retinopathy. Of these, 2,010 have severe diabetic retinopathy that is likely to result in significant and potentially certifiable sight loss.

2.7.2 Strokes

Over 70% of strokes occur in people over 65, and around 60% of people who experience strokes also experience some form of visual impairment immediately after the stroke.

2.7.3 Learning Disabilities

People with learning disabilities are 10 times more likely to experience sight loss than the general population. However, the life expectancy of women with learning disabilities is 65 years, and for men, it is 66 years. As a result, there are relatively few older people with learning disorders and severe sight loss. In Birmingham, it is estimated that 1,610 adults have both a learning disability and partial sight. 365 people with a learning disability over 65 are registered with Birmingham City Social Care¹⁹².

2.7.4 Hearing Impairment

In Birmingham, it is estimated that 90,800 people have a moderate or severe hearing impairment, and 1,980 people have a profound hearing impairment¹⁹³. An estimated 5,680 people live with some degree of dual sensory loss in Birmingham. Of these people, it is estimated that 2,220 live with severe dual sensory loss. In Birmingham, the 2019/20 register of blind and partially sighted people records that 1,690 are registered with a vision impairment and are hard of hearing.

2.7.6 Falls

Falls are common in older people, and the more elderly the person is, the more likely falls will have serious outcomes¹⁹⁴. In Birmingham¹⁹⁵, it is estimated that:

- 3,270 people with sight loss aged over 65 experience a fall per year.
- Of these falls, 1,550 are directly attributable to sight loss.
- 260 people over 65 with sight loss experience a severe fall per year, resulting in hospital admission through A&E.
- Of these severe falls, 120 are directly attributable to sight loss.

In Birmingham, 110 people are registered with a vision impairment and diagnosed with mental health problems¹⁹⁶. A systematic review of studies of sight loss¹⁹⁷ in the elderly found that between 29% and 43% of over 75s with sight loss had significant depressive symptoms compared with between 13% and 27% of over 75s without significant sight loss. Depressive symptoms were associated with high levels of reported isolation and loneliness.

LIFE EXPECTANCY

People who have severe sight loss tend to have lower life expectancy than sighted people primarily because of associated life-threatening conditions such as dementia and strokes



IMPACTS OF COVID-19

During the pandemic, those with Sight Loss had additional barriers when accessing



SHOPPING AND GROCERIES



HEALTH AND SOCIAL SERVICES



VACCINATION CENTRES

WELLBEING The COVID-19 pandemic has also widened some pre-existing gaps in terms of wellbeing



INCREASE IN ISOLATION AND LONELINESS



INCREASE IN MENTAL HEALTH PROBLEMS



INCREASE IN EYE DETERIORATIONS AND CO-MORBIDITIES

2.8 Closing the Gaps

2.8.1 Life Expectancy

Although there are no statistics for the life expectancy of people with sight loss in the UK, several studies have established that life expectancy for people with sight loss is significantly shorter than for people who have no sight loss. In a systematic review of 17 studies of sight loss and mortality,¹⁹⁸ evidence showed that life expectancy decreased as the severity of the sight loss increased. Expressed as a Hazard Ratio, the greatest mortality risk was amongst those with severe vision impairment or blindness (1:1.89), compared with less risk of mortality for those with mild impairment (1:1.29).

A review of 13,569 patients from 49 UK GP practices¹⁹⁹ examined the hazard ratios for the different eye diseases. It found that for AMD, there was a hazard ratio of 1.40, and for cataracts, 1.35. However, after removing the confounding effects of other health conditions, the review reduced the hazard ratio to 1.01 and 1.04, respectively.

The authors concluded that, although the various eye diseases common amongst the elderly are not, in themselves, life-shortening, people with these conditions do have a reduced life expectancy. The impact on life expectancy results from two factors: the consequences of sight loss and the association of sight loss with other health conditions that are life-shortening^{200 201}.

One of the consequences of severe sight loss is that it increases the likelihood of falls that lead to hospitalization. Some falls prove fatal, which is mainly the case for people in the very old age bands. The rate of fatal falls is 8.61 per 10,000 people aged over 75 compared with 0.62 for people aged between 60 and 64.

Amongst the associations with other conditions, the lower life expectancy of people with learning disabilities has been noted in section 8. Diabetes UK estimate²⁰² that people with Type 1 diabetes may have their life expectancy reduced by 20 years, and for people with Type II diabetes, the reduction may be up to 10 years. Life expectancy for people who have had strokes may be shortened by 5 to 10 years depending on the type of stroke: 1 in 4 people die within one year of having a stroke²⁰³.

2.8.2 The Unequal Opportunities of People with Severe Sight Loss

Sight loss is a broad category that extends from people who have a temporary visual impairment to those living with a permanent incapacity that seriously inhibits their life opportunities. Most people have a temporary sight problem; for example, they need a refractive error-correcting, and if they are prescribed suitable spectacles, they have 'normal' sight once again. However, a significant group at the other end of the spectrum has severe sight loss, are blind or have partial sight, and has to live with these disabling conditions. On a wide variety of fronts, the second group have much less opportunity in life than sighted people. There are considerable gaps in what people with severe sight loss can achieve in society compared with people with normal sight. These inequalities can be found in the areas discussed below:

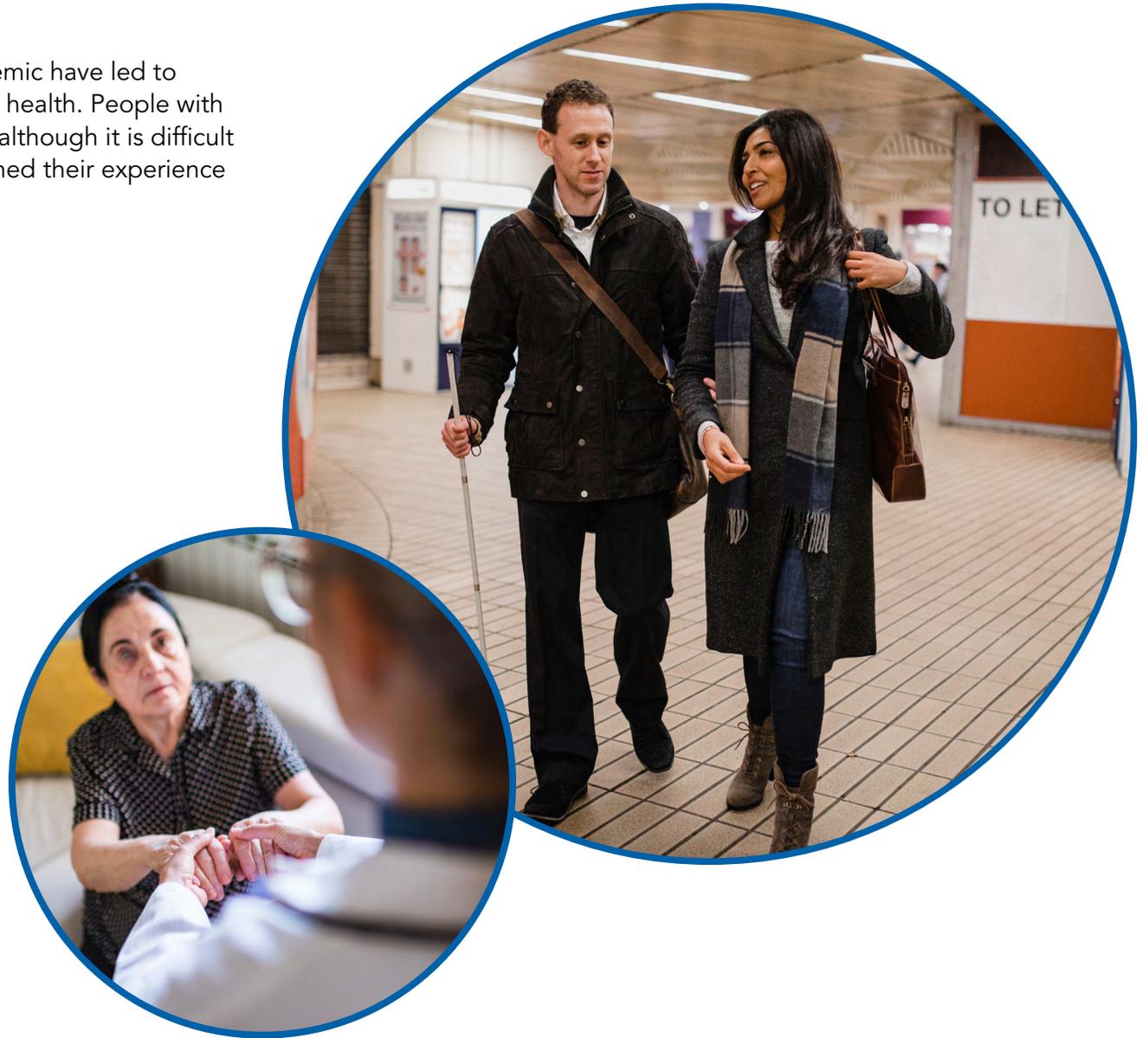
- Whilst educational opportunities at primary school for blind or partially sighted children enable them to make a good start in education, these children steadily drop behind in attainment through secondary and tertiary education. There are relatively few blind and partially sighted students at the university and college level that achieve a higher education award.

- People who are blind or partially sighted tend to become isolated and lonely in their homes and experience many mobility problems when leaving home. Few of them are in employment, and they may experience severe financial difficulties. These factors contribute to a high level of mental health problems.
- To engage in the world as sighted people do, blind or partially sighted people need support. They may receive appropriate medical support to manage their condition, but the social care structure that supports their wider life needs is fragmented and slow. Too often, there is no coordinated support plan, and support relies on friends and families.
- People with severe and permanent sight loss usually have other serious health conditions, notably learning disorders, diabetes and dementia. Apart from the difficulties of managing several conditions, the other conditions also make it more difficult for the issues of sight loss to be addressed; for example, a learning disability or dementia may make it more difficult for a person who is blind or partially sighted to engage with the medical profession: to attend screening sessions, manage medication, achieve greater mobility etc.
- The majority of severe sight loss occurs in old age and becomes more prevalent with advanced old age. It can have a very harmful effect on the quality of life in old age, leading to even more isolation, loneliness and depression. In a complex way, the very common association with other serious health conditions, for example, strokes and dementia, can also lead to reduced life expectancy.

Although all the above inequalities can affect anybody with severe sight loss, the impacts are particularly extreme for the Black and Minority Ethnic communities and people in areas of multiple deprivations. People in these communities with severe sight loss have additional problems navigating the complex health and social care system to receive the help and support they need.

2.9 Mitigating the Legacy of Covid-19

The lockdowns and other restrictions during the pandemic have led to many people experiencing loneliness and poor mental health. People with severe sight loss already face these deprivations, and, although it is difficult to quantify the impact, the pandemic has likely deepened their experience of isolation from the rest of the community.



3.0 Conclusions

The scale of sight loss and the fact that it can occur at any stage in life makes it a major public health challenge for any nation. As a developed nation, the UK has made major strides in treating many sight loss conditions and has an extensive health and social care system to detect, treat and manage the condition. Nevertheless, there remain many challenges to address, and for people with severe sight loss, life can be very restrictive, and wellbeing can be very poor. Seventy per cent of sight loss develops in the elderly. Because the UK has an increasingly ageing population, there is predicted to be a significantly increasing demand for sight loss in the health and social system.

Approximately 50% of sight loss goes undetected at an early stage and can lead to serious sight problems at a later stage. A major challenge is reaching the communities with low take up rates for regular screening.

For the people with severe sight loss who are blind or partially sighted, life can be very restricted, well-being can be hard to achieve, and life expectancy can be limited. Many become isolated and lonely, and mobility problems can restrict access to employment, education, physical activity and other kinds of engagement with normal community life. People with severe sight loss are also likely to have other serious health concerns, and the majority are elderly. A key objective needs to strengthen the current health and social system to provide a comprehensive and timely support system for this vulnerable population.



4.0 Appendix

Appendix 1: Availability of ECLO support by NHS Trust in Birmingham

Birmingham and the Black Country Area Team	Ophthalmic outpatient appointments 2019/20	RNIB-trained ECLOs (Jan 2021)
Birmingham Women's And Children's NHS Foundation Trust	10,745	No
Sandwell and West Birmingham Hospitals NHS Trust	142,310	Yes
The Dudley Group NHS Foundation Trust	35,875	Yes
The Royal Wolverhampton NHS Trust	74,695	Other forms of support
University Hospitals Birmingham NHS Foundation Trust	121,385	Yes
Walsall Healthcare NHS Trust	12,825	No

Source: RNIB Sight Loss Data Tool v4.3.1: Birmingham

Appendix 2: Unaddressed Visual Impairments

Visual Impairment Categories	Cases (Millions)
Uncorrected Presbyopia	826
Unaddressed Refractive Error	123.7
Cataract	65.2
Glaucoma	6.9
Corneal Opacities	4.2
Diabetic Retinopathy	3
Trachoma	2

Appendix 3: Age distribution for Blind and Partially Sighted People in England

Age	Partial sight/Sight impaired persons	Blind/Severely sight impaired persons
0 to 4	470	520
5 to 17	5,145	4,010
18 to 49	18,030	19,020
50 to 64	16,585	19,010
65 to 74	14,710	15,160
75+	85,445	78,175
Totals	140,390	136,300

Appendix 4: Distribution of Certificate of visual impairments across the UK

Country	Distribution of CVIs
England	83%
Wales	5%
Scotland	10%
N. Ireland	2%

Appendix 5: Preventable Sight Loss Indicators 2019/20

PH Outcomes Framework Indicator	Birmingham (Proportion per 100,000)	England (Proportion per 100,000)
E12d Sight Loss Certification	37.4	41.4
E12c Diabetic Eye Disease	4.6	2.9
E12b Glaucoma 40+	9.2	12.9
E12a AMD 65+	98.4	105

Appendix 6: The Employment Status of People with Visual Impairment

Age	Employment	Unemployment	Student	Retired	Long Term Sick or Disabled
18-29	33%	22%	22%	0%	17%
30-49	44%	13%	1%	4%	32%
50-64	22%	9%	0%	19%	45%

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