

UK Vision Strategy

Setting the direction for eye health and sight loss services



**A VISION 2020 UK initiative
led by RNIB**

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Foreword



The UK is one of the richest nations in the developed world and yet it is failing its citizens because the UK's provision of eye health and sight loss services is unfit to meet current and future needs.

Too many UK citizens do not understand the impact of their lifestyles and health conditions on their sight and there is limited public health information and action to help them.

Too many people are living with sight loss that could have been avoided through earlier detection or treatment. And too many people who have lost some or all of their sight do not receive the support they need to enable them to deal with the emotional trauma of sight loss or manage basic everyday tasks.

And despite equality and human rights legislation there is discrimination throughout society that excludes and marginalises people with a visual impairment, often because of ignorance of the impact of sight loss.

Over the years some steps have been taken to improve eye health and sight loss services, but, although this progress is welcome, much more needs to be done to deliver the services that the people of the UK have a right to expect.

The UK Vision Strategy aims to:

- Improve the eye health of the people of the UK.
- Eliminate avoidable sight loss and deliver excellent support to those with a visual impairment.
- Enhance the inclusion, participation and independence of blind and partially sighted people.

The Strategy is the key to achieving changes that are desperately needed. It has been developed by a wide range of individuals from across health and social care bodies,

voluntary organisations, service users and professional groups. The development has been supported by representation from all the UK governments.

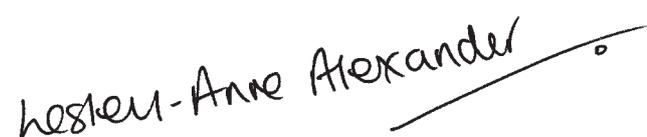
The Strategy points to a society where services are centred on the needs of individuals; a society where health and social care services are truly integrated. It calls for an environment where all UK citizens have access to a straightforward process for maintaining their eye health and where people with sight impairments receive timely and appropriate services.

For service providers, the Strategy calls for a clear route to follow and demands changes that will lead to more rational and cost-effective methods of operating and using resources.

The UK Vision Strategy builds on past progress. It also signals a step change in the eye health and sight loss sector's commitment and willingness to work together. I am sure I am not exaggerating when I say that this is a unique opportunity for us all to make a real and lasting difference to the eye health of the nation and to improve the position of people who have lost some or all of their sight.

I am immensely proud to have chaired the Strategic Advisory Group that steered the development of the Strategy and would like to take this opportunity to give my heartfelt thanks to everyone involved in this journey so far. However, I am also acutely aware that this is only the beginning of the journey and that the real hard work is ahead.

The Strategy is both ambitious and aspirational but I know it is also realistic and achievable. It is imperative that everyone who is concerned with improving eye health, eliminating avoidable sight loss and enhancing the quality of life of people who have lost some or all of their sight unites to deliver its aims.

A handwritten signature in black ink that reads "Lesley-Anne Alexander". The signature is written in a cursive style and is positioned above a horizontal line.

Lesley-Anne Alexander
Chair, UK Vision Strategy Strategic Advisory Group
Chief Executive, RNIB

UK Vision Strategy executive summary

The UK Vision Strategy responds to shortfalls in the UK's eye health and sight loss services by setting out a framework for development. It also addresses widespread ignorance and apathy about eye health. It seeks the following Strategy Outcomes, each of which has specific aims to be achieved over the next five years:

Strategy Outcome 1 Improving the eye health of the people of the UK

Five-year aim: To raise awareness and understanding of eye health among the public, including those people most at risk of eye disease, to allow every individual to develop personal responsibility for eye health and to achieve maximum eye health for all. To raise awareness of eye health among health and social care practitioners, and to ensure the early detection of sight loss and prevention where possible.

Strategy Outcome 2 Eliminating avoidable sight loss and delivering excellent support for people with sight loss

Five-year aim: To improve the coordination, integration, reach and effectiveness of eye health services, and services and support for those people with permanent sight loss.

Strategy Outcome 3 Inclusion, participation and independence for people with sight loss

Five-year aim: To improve the attitudes, awareness and actions of service providers, employers and the public towards people with sight loss and to remove significant barriers to inclusion, so that people with sight loss can exercise independence, control and choice. To achieve improved compliance with disability discrimination legislation.

The Strategy was developed by a wide-ranging alliance of statutory health and social care bodies, voluntary sector organisations, eye health professionals and service users. This powerful combination gives the Strategy a credibility that cannot be ignored. The Strategy Outcomes and Priority Actions have been defined by the combined voices of all these groups, and the many individuals who have contributed. The Strategy Outcomes and Priority Actions align with the health and wellbeing goals of all the UK governments.

The Strategy is underpinned by the following values:

- Fair and equitable access for all members of society to eye health, eye care and sight loss services.
- Person-centred delivery of excellent services and support in the most appropriate way for each individual.
- Evidence-based policies and services to guide resource allocation and effective services.
- Awareness of and respect for people with sight loss and full compliance with equality legislation.

The Strategy seeks a major change for the better in the UK's eye health, eye care and sight loss services: a determined and united cross-sector approach will make that change a reality.

Introduction

The UK Vision Strategy responds to the World Health Assembly Resolution of 2003, which urged the development and implementation of plans to tackle vision impairment, now known as VISION 2020 plans. The UK government has pledged its support for the resolution. The Strategy has been developed by a strong and united alliance of statutory health and social care bodies, voluntary organisations, eye health professionals and service users. Government representatives from across the UK have been involved in its development.

Following a symposium to agree the priorities for change, a draft document was developed and subjected to wide-ranging consultation. Responses were received from more than 650 organisations and individuals. This feedback strengthened the Strategy itself and will also help the development of implementation plans.

The UK Vision Strategy has three Strategy Outcomes and identifies the Priority Actions needed to achieve radical change and improvement. It provides a high-level framework for change, and the subsequent development of implementation plans will translate the Strategy into change on the ground. Such plans should implement the Strategy's Priority Actions in ways that address the needs of all age groups, including children and young people. Plans will also have to respond to specific barriers faced by groups such as people of Black and Minority Ethnic origins and those with learning and complex disabilities.

Development of new policies and services must be based on the best possible evidence. Failure to do so not only risks a waste of resources, but would deny the best care for service users for decades to come, as, once established, management practices can be very difficult to change. Coordination and prioritisation of research is required urgently to support the delivery of the UK Vision Strategy. A national, cross-sector research programme should be defined by a multi-disciplinary group reporting to the UK forum (see the section "Leadership for implementation" starting on page 17) and other stakeholders.

Research needs to focus on improving understanding of the nature and distribution of sight loss (epidemiology), diagnosis, prevention and cure of blindness, the optimisation of services for people with sight loss (including health economics), and the development and validation of new treatments for sight-threatening and correctable conditions.

Specific attention needs to be paid to strategies for the coordination and funding of research as well as dissemination of results. Data on the causes of sight loss and on individuals of all ages with sight loss should be regularly coordinated and analysed to facilitate effective future planning.

The UK Vision Strategy implementation plans will need clear objectives which will be monitored to ensure that progress is maintained. This will include regular reviews.

No strategy can stand still, due to the speed of external change and the evolving needs and expectations of individuals. A major consultation and revision of the UK Vision Strategy is envisaged every five years.

Strategy Outcomes and Priority Areas

This section sets out the future direction for eye health and sight loss services. Focusing on the three Strategy Outcomes below will lead to radical change.

Strategy Outcome 1

- Improving the eye health of the people of the UK

Strategy Outcome 2

- Eliminating avoidable sight loss and delivering excellent support for people with sight loss

Strategy Outcome 3

- Inclusion, participation and independence for people with sight loss

For each Strategy Outcome, there is a five-year aim with Priority Actions which need to be addressed and implemented to make significant progress towards the Strategy Outcomes over the next five years.

Values

Throughout the UK Vision Strategy, references to ‘people’ encompass adults, young people and children, unless specifically designated otherwise.

The UK Vision Strategy is underpinned by core values. These are:

- Fair and equitable access for all members of society to eye health, eye care and sight loss services.
- Person-centred delivery of excellent services and support in the most appropriate way for each individual.

- Evidence-based policies and services to guide resource allocation and effective services.
- Awareness of and respect for people with sight loss and full compliance with equality legislation.

Strategy Outcome 1 **Improving the eye health of the people of the UK**

Five-year aim: To raise awareness and understanding of eye health among the public, including those people most at risk of eye disease, to allow every individual to develop personal responsibility for eye health and to achieve maximum eye health for all. To raise awareness of eye health among health and social care practitioners, and to ensure the early detection of sight loss and prevention where possible.

Priority Actions

- 1.1 Making eye health a public health priority, via on-going, targeted public health campaigns, to increase understanding of the impact of specific health conditions and lifestyles on eye health. Impact on eye health and sight should become an integrated feature of major public health and education campaigns, such as those which tackle smoking or obesity.
- 1.2 Increasing understanding of eye health through cross-sector education and campaigns that concentrate specifically on eye health and emphasise the importance of regular sight tests.
- 1.3 Increasing the understanding of eye health among health and social care and education practitioners, through existing and new training and development programmes. Professionals working with groups at a higher risk of sight loss should be prioritised.

- 1.4 Identifying and addressing potential sight loss among children and young people, including early detection of both sight-threatening and correctable conditions. Plans should include increasing awareness of and access to sight tests, and screening programmes that follow existing best practice and are kept under review.
- 1.5 Identifying and addressing potential sight loss for all individuals with health conditions where sight loss is a known correlate and for groups known to be at increased risk of eye disease. Plans should include increasing awareness of and access to sight tests, and screening programmes that follow existing best practice and are kept under review.

Strategy Outcome 2

Eliminating avoidable sight loss and delivering excellent support for people with sight loss

Five-year aim: To improve the coordination, integration, reach and effectiveness of eye health services, and services and support for those people with permanent sight loss.

Priority Actions

- 2.1 Removing cultural, geographical and financial barriers to eye health and sight loss services for all individuals, ensuring that the needs of disadvantaged groups are considered in particular. This should include specific groups whose take-up of services is low and who may also be at higher risk of sight loss. Such groups will include (but are not exclusive to) people with complex needs or people from Black and Minority Ethnic groups.
- 2.2 Commissioning fully integrated and effective eye care and sight loss services, including low vision services. This should ensure the integration of primary and secondary eye care to achieve the most effective, timely and

accessible services and treatments for each individual, and the best use of community and hospital resources. Services should be person-centred and create seamless pathways through health, social care and the voluntary sector.

- 2.3 Eye care and sight loss services should include emotional support as an integrated part of the service. Services such as counselling should be available to users and to those supporting them as soon as a potential problem is identified. Links to peer support networks should also be offered.
- 2.4 The wider impact of blindness on independence and quality of life is not sufficiently acknowledged. Assessments, from the initial stage onwards, should consider daily living, mobility needs and communication needs, and should be followed up at regular intervals. Services, support, community equipment, housing adaptations or a personal budget should be provided, when required, to enable blind and partially sighted people to exercise choice and control in their lives. The traditional model of rehabilitation should be reviewed to ensure that the support package provided meets the needs of modern living.
- 2.5 Services for disabled and older people should be easy to access and have easy referral paths to eye care and sight loss services, so that individuals experiencing other major health conditions or disabilities do not miss out on eye care and sight loss support.
- 2.6 Service users should be able to make informed decisions relating to their treatment, care and support. Where the user would find it helpful, those who support them or an independent advocate should be involved.
- 2.7 All organisations should encourage a meaningful role for user groups in the design of services and their delivery and development.

- 2.8 Reliable, accessible and relevant information on eye conditions, eye care, sight loss services, support networks and legal entitlements should be easily available in a range of formats, to enable people to understand their options, select services and make informed decisions.

Strategy Outcome 3 Inclusion, participation and independence for people with sight loss

Five-year aim: To improve the attitudes, awareness and actions of service providers, employers and the public towards people with sight loss and to remove significant barriers to inclusion, so that people with sight loss can exercise independence, control and choice. To achieve improved compliance with disability discrimination legislation

Priority Actions

- 3.1 Increasing awareness of rights and services among all individuals with sight loss, and their families, parents and carers, through cross-sector awareness campaigns. Greater awareness will result in improved uptake of services and increased confidence in seeking equal treatment.
- 3.2 Education and vocational training should be accessible to people of all ages with sight loss. Children and young people should be assured full access to the curriculum and equality of opportunity and participation, including social activities, throughout their education. Children with sight loss and additional or complex disabilities should receive the best possible education and care.
- 3.3 A clear and smooth transition pathway from children's and young people's services to adult services should be established or maintained, to ensure that rights to benefits and support are not lost during this process and young people are enabled to fulfil their potential. This applies equally to health services and social care services.

Broader integration of these services with other services such as education and employment is also needed.

- 3.4 People with sight loss should have equal access to job opportunities and the present negative attitudes should be tackled. Employers should ensure that their recruitment and employment processes do not discriminate against people with sight loss, preventing them from gaining or retaining employment. This should be assisted and supported by government initiatives. There should be opportunities for supported employment for people with sight loss and additional disabilities. Awareness of the Access to Work scheme should be raised among employers.
- 3.5 Benefit provision should recognise the additional financial costs arising from sight loss and should be adjusted accordingly, to assure equality of opportunity and quality of life.
- 3.6 Current and future advances in technology should be made readily available to people with sight loss, in particular the continuing development of the web and mobile communication technologies. This should include low-cost, affordable adaptations and equipment. Training in the use of new technologies should be available, affordable and on-going.
- 3.7 Leisure activities should be accessible to everyone with sight loss, including (but not exclusive to) sport, exercise, holidays, hobbies, television, radio, reading, films and the visual and performing arts.
- 3.8 Public and commercial services should be fully accessible to people with sight loss.
- 3.9 Moving around the external environment safely should be made as easy as possible for people with sight loss. This involves clear pavements, safe crossings and bold signage. Transport providers need to make their services fully accessible. Additional travel costs need to be recognised by the benefits system.

Leadership for implementation

Cross-Sector Forums

Delivery of the UK Vision Strategy requires a united eye health and sight loss sector that focuses on the implementation of the Strategy, speaks with one voice and strongly influences the direction of decision makers and UK governments.

Leadership and implementation arrangements should be put in place to provide guidance that will translate the UK Vision Strategy into genuine change.

It is vital that the leadership bodies which drive the implementation of the UK Vision Strategy mirror government arrangements for the setting of priorities and the allocation of resources. Leadership bodies may be created specifically for this purpose or be formed by restructure of existing bodies. Governments across the UK (England, Northern Ireland, Scotland and Wales) are responsible for health and social care within their respective countries, and service priorities and arrangements differ. The leadership model for the UK Vision Strategy needs to recognise this divergence across all areas of provision. It is therefore proposed that leadership takes the form of a UK forum and four country-specific bodies. Due to the population size of England, local arrangements may be developed.

A UK forum will provide leadership and momentum for the implementation, monitoring and reviewing of the Strategy. The forum will include designated roles for the different players within the eye health and sight loss sector, to ensure continued cross-sector dialogue and action. The Strategic Advisory Group that led the development of the UK Vision Strategy will fulfil this role, pending the establishment of a UK forum.

Due to country-specific arrangements for the delivery of health and social care services, each country will need to establish a forum to ensure national leadership and national delivery plans for the UK Vision Strategy. These plans will ensure that links are made to wider government strategies, plans and policies, providing direction and guidance for local implementation. These country forums will need to be led or strongly supported by the relevant government.

All forums will need to call upon experts for different aspects of the UK Vision Strategy, depending on the existing expertise of their own members.

Statutory, Voluntary and Commercial Organisations

All organisations with a stake in eye health and sight loss issues should ensure that their strategy supports the delivery of the UK Vision Strategy. All such organisations should carefully consider the UK Vision Strategy and the role they can play in making it a reality. Co-ordination of effort across all sectors should be the ultimate aim.

User involvement and feedback should be included at all stages of the Strategy's implementation, to ensure that the services provided meet users' needs.

All organisations formed to meet the needs and support the interests of blind or partially sighted people should ensure there is leadership within their organisation from people who are blind or partially sighted.

Partnerships across other sectors relevant to eye health and sight loss issues, such as those which deal with diabetes, stroke and the needs of older people or early-term babies, should be developed to increase understanding and cooperation on areas of common concern.

Cross-Sector Relationships

Representative bodies within the eye health and sight loss sector should consider how they can support the implementation of the UK Vision Strategy. Barriers to inter-professional and inter-organisational working and collaboration should be identified and removed, and ways that service delivery would be supported by rationalisation of bodies and professions should be identified.

The Case for Change

This section summarises the reasons why change is essential in each of the three Strategy Outcome areas. Services are already failing to meet current needs and there can be no doubt that there will be increased demand in the very near future. Demographic forecasts show that by 2021, 40 per cent of the population will be over 50; a significant proportion of sight loss is related to age and one in eight over-75s and one in three over-90s have serious sight loss [Evans JR et al. Prevalence of visual impairment in people aged 75 years and older in Britain. *British Journal of Ophthalmology* 2002]. Diabetes, and hence diabetic retinopathy, among children and young adults is also increasing and this too will prove a challenge to service providers. At the same time, research suggests a clear economic case for early and effective intervention: an Australian study has found that for each dollar spent on eye care and the prevention of sight loss, there could be a five-dollar return to the community [Taylor HR et al. Costs of interventions for visual impairment. *American Journal of Ophthalmology* 2007].

Improving the eye health of the people of the UK

Sight loss is even more feared than cancer, AIDS, stroke, heart disease or diabetes [American Foundation for the Blind 2007]. Yet many people are simply not aware of the vital importance of caring for their eyes. Both smoking and obesity can double the probability of sight loss [various studies, see Appendix B].

The early stages of many eye diseases show no symptoms, so that, by the time symptoms manifest themselves, the disease may already be advanced. However, many eye conditions, such as glaucoma, one of the main causes of blindness, are treatable if detected early enough.

Failure to invest in early detection and treatment of eye conditions means increased spending on health, social care, education and training to support people in the later stages of eye disease. Therefore, there is a sound moral and economic case for early intervention. Australian research has shown a four-fold return on investment in early eye care intervention [Taylor H R et al. Costs of interventions for visual impairment. American Journal of Ophthalmology 2007]. The total costs of sight loss in the UK have been estimated at £4.9 billion a year [Winyard S. The Costs of Sight Loss in the UK. RNIB 2005]. Indirect costs such as those relating to falls or increased care costs are also significant; for example, the medical cost of falls related to visual impairment was estimated at £128 million over a 12-month period. [Scuffham PA et al. The incidence and cost of injurious falls associated with visual impairment in the UK. Visual Impairment Research 2002 April Vol 4, 1-14].

Many children are not receiving the eye care they need and could therefore be disadvantaged in fulfilling their potential. Children are not being screened for potential eye problems, nor are they receiving regular sight tests. The 2003 report Health for All Children [Hall DMB, Elliman D. Health for All Children. Oxford University Press 2003] recommends screening of newborns for eye abnormalities and orthoptic-led screening of four to five-year-olds for vision defects. However, these recommendations have not been universally implemented [British and Irish Orthoptic Society survey 2007], risking later diagnosis and poorer outcomes. In addition, the Health for All Children report recommends straightforward access for children to eye care services; parents should be able to enter a planned referral pathway from first suspicion to diagnosis and management. The report also called for further research, and for parents to be made aware of the availability of NHS sight tests for under-16s (under-19s if in full-time education).

Eliminating avoidable sight loss and delivering excellent support for people who are losing their sight

There is inconsistent integration of primary and secondary eye care services. Services that could be delivered in a primary care setting are still often based in hospitals, leading to backlogs, and community resources are in the main vastly under-utilised. Some poorer socio-economic areas and rural areas are not properly served by high street opticians.

A lack of awareness of eye health among the general public and among a large number of health, social care and education professionals, together with an absence of systems for reaching at-risk groups, leads to late presentation for treatment. Age-related macular degeneration, glaucoma and diabetic retinopathy have all increased in England and Wales since 1990-91 and figures for diabetic retinopathy among the over-65s have more than doubled [Bunce C, Wormald R. Leading causes of certification for blindness and partial sight in England and Wales. BMC Public Health 2006].

Health, education and social care services for adults and children with sight loss are very variable and links between health, education and social care can often be poor. This leads to a failure to support individuals and their families adequately. [Boulton, M et al. Families of young children with visual impairment. Oxford Brookes University/Imperial College London 2004; Keil S et al. Shaping the Future. RNIB 2001; Rahi JS et al. Health services experiences of parents of recently diagnosed visually impaired children. British Journal of Ophthalmology 2005.]

Emotional support, including counselling, is almost non-existent, despite the acknowledged trauma of sight loss. The absence of such support often means that people will be much slower to regain their confidence and learn new skills. The prevalence of depression is at least twice as high in visually impaired older adults than in older people with good vision [Evans JR et al. Depression and anxiety in visually impaired older people, Ophthalmology 2007].

Visual impairment is also associated with a higher risk of suicide [Waern M et al. Burden of illness and suicide in elderly people. *British Medical Journal* 2002]. However, only 20 per cent of low vision and rehabilitation service providers have links to counsellors [McLaughlan B et al. A Question of Independence. RNIB/AMD Alliance 2006].

Groups at greater risk of sight loss also tend to be those most vulnerable to exclusion from services. Such groups include older people, people in the lower socio-economic groups, those in residential care, those with poor mobility, those with dementia, Black and Minority Ethnic (BME) groups, those with multiple sensory loss/impairment, those with communication difficulties, those with learning difficulties, the prison population, asylum seekers, refugees and travelling populations. For example, the risk of sight loss is higher among people from lower income groups and BME groups; BME groups represent a significant expanding ageing population and are expected to have a higher prevalence of some common age-related eye diseases [Tate, R et al. The prevalence of visual impairment in the UK. RNIB/Vision 2005].

Information about available services varies considerably, as do user expectations [Better information, better choices, better health. Department of Health 2004; Choosing Health – Making Healthier Choices Easier. HMSO 2004]. This prevents individuals from exercising choice and control; it is even more difficult for those who have not reached the threshold for registration or who are no longer receiving medical care [Barry R, Murray P. Unregistered visual impairment: is registration a failing system? *British Journal of Ophthalmology* 2005].

When social care assessment fails to identify the serious consequences of being blind or partially sighted, people may receive little or no support [Dementia and serious sight loss. Thomas Pocklington Trust 2007]. Many do not receive even the minimum equipment they need to assist them with mobility, communication and everyday tasks [Buy your own white stick! RNIB 2005]. There is a significant shortfall in the number of qualified rehabilitation workers for adults and independence specialists working with children; numbers of

workers trained in visual impairment have reduced over the last five years [Independence and Wellbeing in Sight. Guide Dogs/Rehabilitation Project Group 2007].

Inclusion, participation and independence for people with sight loss

Three out of four blind or partially sighted older people live in poverty or on its margins, living on less than half the mean national income [Unseen. Neglect, isolation and household poverty amongst older people with sight loss. RNIB 2004].

Only 34 per cent of blind and partially sighted people are in employment, compared to 75 per cent of the population overall [Douglas et al. Network 1000: Opinions and circumstances of visually impaired people in Great Britain. VICTAR/VISION 2020 UK 2006].

24 per cent of blind and partially sighted people of working age have no qualifications, compared to 15 per cent of the working age population [Pey, T et al. Functionality and the Needs of Blind and Partially Sighted Adults in the UK. Guide Dogs 2007].

Gaps in the transition from children's and young people's services to adult services, which have different funding mechanisms and criteria, may mean that young people do not receive the support or information they need to enable them to fulfil their potential and maintain control of their lives [Special Educational Needs SEN Regional Partnerships Case Study 7: Transition planning. DfES 2003].

Over 180,000 registered blind and partially sighted adults in the UK never or rarely go out because the social care system does not meet their needs [Pey, T et al. Functionality and the Needs of Blind and Partially Sighted Adults in the UK. Guide Dogs 2007]. The cost of public transport, coupled with access difficulties, reduces mobility. Housing is often too far from local amenities, or poorly connected to these.

Public buildings such as theatres, cinemas and libraries, and even hospitals and surgeries, are often not designed to be accessible, leading to isolation and social exclusion of blind and partially sighted people.

Design fails to take into account the needs of people with sight loss, in particular those who are blind and partially sighted. Areas that fall short include (but are not exclusive to): transport; signage for those on foot; food labelling; medicine labelling; white goods and technology (for example, mobile phones with small buttons and poor contrast); the written word – less than 5 per cent of books are available in accessible formats [Lockyer S et al. Availability of accessible publications. RNIB/Loughborough University, 2004].

Disability discrimination legislation is too often not enforced.

Conclusion

The UK Vision Strategy is a bold and challenging framework for the transformation of eye health and sight loss services across the UK.

Eye health and sight loss services cannot afford to stand still, given the shortfalls in current services and the extra demands that the near future holds. The UK Vision Strategy, based on a united, cross-sector approach and user-centred principles, has been designed not only to address the failings that have been identified, but also to provide the impetus to develop services that will meet the needs of the future.

Stakeholders from across the sector were involved in drawing up the Strategy: it represents the voices, concerns, priorities and needs of diverse professional, health, education, social care and user groups. This united and cooperative stance has proved highly effective in formulating the Strategy; if this can be maintained for delivery, it bodes well for ultimate success.

Appendix A

Development of the UK Vision Strategy

The UK Vision Strategy responds to the World Health Assembly Resolution 2003, which urged the development and implementation of VISION 2020 national plans to tackle vision impairment. The UK government pledged to support this resolution. In April 2007, representatives from across the eye health and sight loss sector met to identify and discuss the key challenges. It was agreed to develop a UK Vision Strategy which the whole sector could support and it was confirmed that this would be a VISION 2020 UK initiative led by RNIB.

Following the symposium in April 2007, a Strategic Advisory Group was formed to lead the development of the Strategy. This comprises representatives from statutory health and social care organisations, voluntary organisations and eye health professionals, as well as government observers.

Over summer 2007, multi-disciplinary teams were set up by the Strategic Advisory Group. These worked on different aspects of the Strategy and in November a consultation document was produced. Between November 2007 and January 2008, eight consultation events were held across the UK and individuals and organisations were invited to make individual responses. Around 200 responses were received and over 450 people gave their views at the consultation events.

In February 2008, the Strategic Advisory Group considered the feedback obtained and incorporated this into a final version of the UK Vision Strategy, launched in April 2008.

The Strategic Advisory Group members

- Lesley-Anne Alexander, chief executive, RNIB
Chair of the Strategic Advisory Group
- Nick Astbury, consultant ophthalmologist/The Royal College of Ophthalmologists
- Rosie Auld, chairman, British and Irish Orthoptic Society
- Mike Brace, chief executive, VISION 2020 UK
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- Stephen Remington, chief executive, Action for Blind People
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- Bridget Warr, chief executive, Guide Dogs
- Jo Webber, deputy policy director, NHS Confederation

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Appendix B

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Appendix C

Evidence base to support the UK Vision Strategy

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Abstract

Sight loss is now a major health issue, affecting about two million people in the UK. The vast majority are older people, although an estimated 80,000 working age people and 25,000 children in the UK are affected by sight problems [Keil S. Key statistics. RNIB, 2008]. Evidence suggests that over 50% of sight loss is due to preventable or treatable causes. This is most marked in the older population, where this proportion is estimated to be between 50% and 70% [Tate, R et al. The prevalence of visual impairment in the UK. RNIB/Vision 2005].

Significant numbers of people also live with irremediable or certifiable sight loss; RNIB estimates suggest around 980,000. The leading causes are age-related macular degeneration (AMD), glaucoma and diabetic retinopathy. In England and Wales, the age-specific incidence of all three has increased significantly since 1990-1991. Cases of diabetic retinopathy show the most marked increase, particularly among the over-65s, where figures have more than doubled [Bunce C, Wormald R. Leading causes of certification for blindness and partial sight in England and Wales. BMC Public Health 2006].

As the population ages and the incidence and prevalence of key underlying causes of sight loss increases, so sight loss is expected to become even more prevalent in the future [Frick KD, Foster A. The magnitude and cost of global blindness. American Journal of Ophthalmology 2003; Taylor et al. The economic impact and cost of visual impairment in Australia. British Journal of Ophthalmology 2006]. Recent global estimates predict that, without intervention, there will be a doubling in the number of blind individuals between 2000 and

2020. The evidence points firmly towards major challenges in improving services to meet need.

Apart from health and social impacts, there are also significant economic impacts resulting from sight loss. RNIB estimates indicate that the total UK costs are in the region of £4.9 billion a year [Winyard S. The Costs of Sight Loss in the UK. RNIB 2005]. These are conservative estimates, however, and more recent and comprehensive Australian studies indicate that vision disorders cost an estimated 0.6% of GDP (A\$9.85 billion in 2004).

Frick and Kymes [The calculation and use of economic burden data, British Journal of Ophthalmology 2006] argue that these findings rank the absolute economic burden of sight loss with that of cancer, dementia and arthritis. 'The impact relative to [an] entire [] economy also emphasises the non-trivial nature of the burden of visual impairment. The results should catch the attention of health policy makers because they suggest that, even in a developed economy, visual impairment can limit economic development.'

As the authors of the Australian study conclude: 'a developed economy cannot afford (avoidable) vision loss. Priority needs to be given to prevent preventable vision loss; to treat treatable eye diseases; and to increase research into vision loss that can be neither prevented nor treated.' Improving diagnosis and early intervention is also crucial, because detecting disease at an earlier stage will also enable more to be done to delay disease progression. Strategies for prevention, early diagnosis and intervention are also likely to be cost-effective. An Australian study has found that for each dollar spent on eye care and the prevention of sight loss, there could be a five-dollar return to the community [Taylor H R et al. Costs of interventions for visual impairment. American Journal of Ophthalmology 2007].

The UK Vision Strategy team thanks Guide Dogs for resourcing this research

Access to the full report is available from the UK Vision Strategy website rnib.org.uk/ukvisionstrategy

Appendix D

Notes on policy

VISION 2020

VISION 2020: The Right to Sight is the global initiative for the elimination of avoidable blindness, coordinated jointly by the World Health Organization (WHO) and the International Agency for the Prevention of Blindness (IAPB) with its international membership of non-governmental organisations (NGOs), professional associations, eye care institutions and corporations.

VISION 2020 member organisations are working together to eliminate avoidable blindness and minimise disability from vision impairment worldwide by the year 2020, to give everyone in the world the Right to Sight.

VISION 2020 globally aims to be comprehensive in terms of:

- prevention, rehabilitation, education, empowerment
- human and infrastructure development to deliver appropriate control strategies
- engagement and ownership with all stakeholders.

More than 50 organisations involved in vision and sight loss have signed up to VISION 2020 UK, the umbrella organisation which promotes the aims of the VISION 2020 global initiative.

Disability Discrimination Act (DDA)

In 1995, after many attempts by backbench MPs to secure civil rights legislation for disabled people, the Government finally introduced the Disability Discrimination Act (DDA). While not fully embracing the civil rights agenda, the DDA went some way to shifting the focus from the needs-based approach to the rights agenda and, since 1995 it has been further strengthened by the measures introduced under the Disability Discrimination Act 2005.

The DDA covers employment, education and access to goods and services (which, following the 2005 Act, now also includes access to public transport services). In addition, it provides for accessibility regulations to be introduced for public transport, which establish the technical requirements necessary to ensure that those services are accessible to disabled people.

Disability Equality Duty (DED)

The Disability Equality Duty (DED) covers the full range of what public sector organisations do – including policy making and services that are delivered to the public. Public sector organisations include: libraries, hospitals, schools and colleges, National Health Service trusts, the police forces and central and local government.

People who work in the public sector have to consider the impact of their work on disabled people, and take action to tackle disability inequality. This should mean that disabled people have better employment opportunities and do not come across discrimination when, for example, using a service. It should also help promote positive attitudes towards disabled people in everyday life.

Since December 2006, significant public authorities have had to publish a Disability Equality Scheme. The scheme must include:

- a statement of how disabled people have been involved in developing the scheme
- an action plan that includes practical ways in which improvements will be made
- the arrangements in place for gathering information about how the public sector organisation has done in meeting its targets on disability equality.

(www.direct.gov.uk)

UN Convention on the Rights of Persons with Disabilities

In December 2006, the draft text of the convention on the rights of persons with disabilities was formally adopted by the General Assembly at the United Nations. The UK was among the first states to sign up to the Convention when it was formally opened for signature and ratification on 30 March 2007.

The purpose of the UN Convention is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all disabled people so they can fully participate in society. It will promote the participation of and respect for disabled people in a wide range of areas of society, and covers aspects such as:

- living independently and being included in the community
- equality and non-discrimination
- the position of disabled women and children
- access to justice
- education
- health
- work and employment
- participation in political and public life
- participation in cultural life, recreation, leisure and sport.

The European Blind Union is currently considering the text of the Convention to establish what actions would be required to meet the needs of blind and partially sighted people. It is clear from the analysis that has been done so far that the Convention will have far-reaching consequences and should lead to real change and improvement in the lives of blind and partially sighted people.

Definition of independent living

The definition of independent living laid down in the Disabled Persons (Independent Living) Bill states that:

‘Independent living’ means disabled persons enjoying the same choice, freedom, dignity, control and substantive opportunities as persons who are not disabled, at home, at work, and as members of the community in order to improve outcomes for disabled persons in relation to:

- (a) Their individual autonomy.
- (b) Their confidence and security.
- (c) Respect for and full enjoyment of their rights to privacy and family life.
- (d) Their participation in education, life-long learning, training and recreation.
- (e) The contribution made by them to society, including their participation in voluntary work and employment.
- (f) Their social and economic well-being.
- (g) Their participation in community and public life.
- (h) Their physical and mental health and emotional well-being.

Appendix E Glossary

Albinism: a condition where there is lack of pigment in the skin, hair and eye (iris and the back of the eye). The vision is impaired and there is also light sensitivity and nystagmus.

Amblyopia: sometimes called 'lazy eye'. This is a condition in which the sight, usually of one eye, does not reach its full potential. The problem is caused by either no visual stimulus or a poor stimulus reaching the brain for a sustained period during early childhood. It is often associated with squint or refractive error.

Cataract: a clouding of the eye's natural lens, often linked to ageing or to diabetes.

Certificate of Visual Impairment (CVI): the registration form for patients eligible for certification as sight impaired (partial sight) or severely sight impaired (blind), which can only be signed by a consultant ophthalmologist.

Diabetic retinopathy: damage to the blood vessels at the back of the eye caused by fluctuating blood sugar levels.

Disability Discrimination Act (DDA): legislation to promote civil rights for disabled people and protect disabled people from discrimination.

Disability Living Allowance (DLA): tax-free benefit for children and adults who need help with personal care or have walking difficulties because they are disabled.

Domiciliary care: care delivered at home or similar.

Glaucoma: a group of disorders often associated with a raised internal eye pressure which can damage the optic nerve and so result in sight loss.

GPwSI: a GP with a specialist interest in ophthalmology.

Low Vision Leaflet (LVL): a self-referral letter sent to social services to request advice and support for problems with vision loss.

Macular degeneration: usually age-related, this is the deterioration of the part of the retina responsible for the sharp, central vision needed to read or drive, for example.

Nystagmus: an involuntary eye movement, usually regular and repetitive.

Ocular hypertension: higher-than-normal internal pressure in the eye, associated with an increased risk of glaucoma.

Ophthalmic medical practitioner: medically qualified, with postgraduate training in ophthalmology, can also issue prescriptions in the same way as optometrists.

Ophthalmic nurse: has general nursing training plus specialist training in eye care, assists in surgery and manages patients with glaucoma, cataract, low vision and other eye conditions.

Ophthalmologist: examines, diagnoses and treats diseases of the eye, prescribes medicine, performs surgery and typically works in a hospital.

Optician (or dispensing optician): advises on and supplies spectacles and low vision aids, and sometimes contact lenses.

Optometrist: examines eyes, tests sight, gives advice on visual problems, and prescribes and dispenses spectacles, contact lenses and other visual aids. Some optometrists may be involved in other aspects of eye care, working with ophthalmologists.

Orthoptist: diagnoses and treats vision defects and abnormal eye movements, usually as part of a hospital care team; orthoptists are also noted for their expertise in matters relating to children's vision.

Personal Child Health Record: a record of a child's growth and development, designed to enhance communication between parents and health professionals.

Primary Care: in relation to the care of eyes, the provision of first contact care for eye conditions. Generally, primary care health services are based in the local community.

Qualified Teacher of the Visually Impaired: QTVIs have extra training in working with children with visual impairment, and work in special and mainstream schools or within visual impairment service teams.

Referral of Visual Impairment (RVI): form sent by hospital eye service staff including optometrists to alert social services (with the patient's consent) that a patient has vision impairment and would benefit from an assessment.

Rehabilitation worker: provides specialist assessment, training and advice to all types of people with a vision impairment; some work within social services, others with voluntary organisations.

Secondary Care: a term used for treatment by specialists to whom a patient has been referred by primary care providers. Secondary care is generally hospital-based.

Sight impaired/severely sight impaired: the terms that recently replaced partially sighted and blind for registration and certification purposes.

Strabismus: sometimes called 'squint'. This is a condition in which the visual axes of the eyes are not parallel, so that one eye appears to be looking in a different direction to the other.

Tertiary Care: a term used for the provision of highly specialised consultative services, usually involving expert investigation or treatment.

UK Vision Strategy – Strategic Advisory Group



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Guide Dogs



EYE HEALTH ALLIANCE



Action for blind people



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