

Seeing it my way

A universal quality and outcomes framework for blind and partially sighted people



A consultation to ensure that every blind and partially sighted person, regardless of where they live in the UK, has access to the same range of information, advice and practical support.



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Introduction

During the last 12 months a group of organisations delivering services to blind and partially sighted people have joined together to try and find a way of ensuring that people with sight loss, their friends, family and carers have access to the same range of information, advice and practical support regardless of where they live in the UK.

This work has been prompted by a number of issues:

- Services are often not known about and can be hard to find.
- Services are not universally available across the UK and are not delivered to a consistent standard.
- Reductions in local authority spending may severely restrict what is available as a statutory service funded by the state.
- There is a real desire on the part of organisations working with blind and partially sighted people to create change.

‘Seeing it my way’ is a major new UK wide initiative which will set out a range of outcomes that blind and partially sighted people have told us are most important to them. The initiative is supported and endorsed by the UK Vision Strategy Advisory Group. ‘Seeing it my way’ is presented as outcomes rather than services because delivery of these outcomes and the organisations that provide them will vary across England, Scotland, Wales and Northern Ireland. Outcomes will be supported by quality frameworks so that regardless of which organisation delivers them, they are of a consistent standard. Outcomes will apply to everyone and are intended to be relevant to people of all ages and those living with other disabilities, for example those with a learning disability, neurological conditions, dual sensory loss, and people from ethnic minority backgrounds.

The purpose of ‘Seeing it my way’ is to influence how services are delivered to ensure that blind and partially sighted people benefit from these outcomes. The initiative represents a significant commitment from organisations in the sight loss sector to work together with common purpose, regardless of whether those organisations are local, regional or national.

This quality framework will inform those who commission services for local authorities about which services are most important to you. It will provide a solid foundation for future lobbying and campaigning activity. Most importantly, it will ensure that every person living with sight loss will have access to the same range of information, advice and practical support, regardless of where they live, delivered to a consistent and high standard.

Working on the principle that blind and partially sighted people should be at the heart of everything that the sight loss sector does, people with sight loss have described outcomes they would like to have in their lives. The outcomes are described from your perspective to emphasise the important philosophy of 'nothing about me without me'. A theme common to all the outcomes is the requirement for everyone working with blind and partially sighted people to use plain English and that all services should aim to maximise independence if that is what is wanted.

What do you need to do now?

We need to hear from you! To make 'Seeing it my way' a reality we need to make sure we have the right outcomes. Those presented for consultation have been developed from existing research and by talking to people with sight loss. However, for this framework to have real authority in the years to come we would like to have the endorsement of as many blind and partially sighted people as possible.

Please take the time to go through the outcomes presented in this document and respond to the questions in the enclosed response form. Every piece of feedback is vital to us, so please don't think your views are not important. Whether you support the approach or not, whether you have any specific comments or not, please respond to this consultation and help us make 'Seeing it my way' the catalyst for achieving the much needed transformation in services for those with sight loss. Find out more about responding to 'Seeing it my way' on page 13.

Summary of 'Seeing it my way' outcomes

- 1** That I have someone to talk to
- 2** That I understand my eye condition and the registration process
- 3** That I can access information
- 4** That I have help to move around the house and to travel outside
- 5** That I can look after myself, my health, my home and my family
- 6** That I can make the best use of the sight I have
- 7** That I am able to communicate and to develop skills for reading and writing
- 8** That I have equal access to education and life long learning
- 9** That I can work and volunteer
- 10** That I can access and receive support when I need it

Outcome 1 That I have someone to talk to

Definition

I want help to come to terms with my condition and to help me address the impact of sight loss on my life. I want that support to be appropriate to my needs, whether it is advice or extended professional counselling. I want to be given dedicated time and support to help me achieve personal well being. This means that:

- I will be offered advice and appropriate support at the point of diagnosis by a trained professional or information service.
- I will be informed about available services to support my emotional needs and if necessary, be helped to access them at the right time and at the right place with acknowledgement that as my condition changes my need for such support might be ongoing.
- I will have access to a well facilitated peer support group.
- If I have additional disabilities, please remember that I may not be able to tell you how my sight loss makes me feel. I may need an advocate.

Outcome 2 That I understand my eye condition and the registration process

Definition

I want to know what my eye condition is and what it means for me and my family and carers. I want someone to talk through the difficulties this may bring to my life. I also want to understand what certification and registration means and the benefits it can offer. This means that:

- I will feel that the medical professionals who diagnose and treat me understand my anxieties.
- They talk to me in language I understand.
- If I have additional disabilities, professionals will understand that I may not be able to explain how my sight has changed and that sight loss may change my behaviour.
- Professionals will involve my family and carers, if that is what I want.
- The certification and registration process will be explained to me and I will be able to access its benefits.

Outcome 3 That I can access information

Definition

I need information in a format that I can access, which tells me about local and national services I can use. I want to know how to link to social services and other agencies that could help me with eligibility for benefits and services, if that is appropriate. This means that:

- I will receive information in my preferred format.
- If I have additional disabilities I may need information in easy to read formats.
- I will be given a link to local social services, if that is what I want.
- The professionals caring for me will have the information I need or they will know how to obtain it.
- I will receive information at the time when I need it.

Outcome 4 That I have help to move around the house and to travel outside

Definition

I want orientation and mobility training to help me to move safely and independently. I want transport and disability benefits to respond to the serious mobility limitations experienced by blind and partially sighted people, which cause isolation and loneliness. I want help and support to get out on my own. This means that:

- I will receive training in mobility delivered by a trained professional, low vision advice about my home and such equipment as is required.
- I will have the opportunity to meet with others and to take part in events and activities.
- I will have access to transport services that take my mobility and sensory restrictions into account.

Outcome 5 That I can look after myself, my health, my home and my family

Definition

I want to look after myself so I need to learn new ways of completing tasks that others take for granted. I have to look after my home, deal with money, do shopping and manage my medication. All these things need me to learn new skills. This means that:

- I have a safe and secure home to live in.
- I will learn to prepare food and to cook safely.
- I will have information about how to keep healthy.
- My bank will send me information in my preferred format.
- I will have access to appropriate benefits to maximise my financial security.
- I will be able to read food and medicine labelling.
- If I have additional disabilities I may need support to be as independent as possible.

Outcome 6 That I can make the best use of the sight I have

Definition

I want to have my remaining sight professionally assessed and then to be taught how to use low vision aids, such as magnifiers. I want to be advised on how to make the most of my sight, such as how to light my home more effectively or to learn new reading methods. This means that:

- My eye clinic or optometrist will refer me to a low vision service.
- I will be trained in the use of the aids prescribed.
- I will be able to revisit the low vision service if my eye condition changes.
- I will have my low vision aids cleaned and be given new batteries if required.

Outcome 7 That I am able to communicate and to develop skills for reading and writing

Definition

I may need magnification or speech technology on my computer, or I may need to learn braille. Special equipment might help me to access reading material or a computer screen. This means that:

- I will be taught computer skills, if I want them.
- I will be offered braille teaching.
- I will obtain information and material I require in the format of my choice.
- If I have additional disabilities I may need easy to read information and tactile clues.

Outcome 8 That I have equal access to education and life long learning

Definition

As a blind or partially sighted child, young person or mature learner, I have a right to education with specialist teaching support to access the curriculum and learning material. This means that:

- My school, university or college will understand my eye condition and the effect it has upon me.
- My school, university or college always offers all material in my preferred format at the same time as my sighted peers receive it.
- My school, university or college will have made adjustments to the environment and its way of working to enable me to participate fully in school and college life.
- My educational and support needs will be met during my transition to further education.
- I will participate in sporting and leisure and social opportunities, if that is what I want.
- I will be taught life skills and independence to enable me to have control and choice in my life.

Outcome 9 That I can work and volunteer

Definition

In order for me to work, I need training and skills development. This means that:

- If I am already in work I need my employer to be informed about how to support me in learning new skills and different ways of working that will help me to retain my job.
- I have the support of an advocate in retaining my employment.
- If I am new to the world of work then I will receive training in my chosen field and support in the search for a job with training and advice on CV writing, and interview techniques.
- I will be able to breakdown the barriers caused by a lack of understanding from my employer and colleagues.

Outcome 10 That I can access and receive support when I need it

Definition

I want my services planned around me and my needs and where appropriate, my own budget for my care. If there are problems, then I want advocacy support to get the best from the services and benefits that are available to me. I want to play a part in society but may need help and support to do that. This means that:

- I can use my budget for self directed care in the way I feel is most appropriate to my requirements.
- I will have access to timely assessment of my requirements by a qualified practitioner.
- I will have access to rehabilitation services both now and at times when my needs might have changed.
- If I run up against difficulties I will be able to access trained advocacy support to act on my behalf.
- I will have a sense of belonging and inclusion and can take part in social, sporting and leisure activities in my community.
- I want to be informed of my rights and my responsibilities.
- My family and carers receive support and advice if it is required.

Be a part of 'Seeing it my way'

We want blind and partially sighted people to be part of this initiative.

This is your invitation to participate. It is your opportunity to make a concerted effort to improve services for people living with sight loss.

Please do respond to our questions and also let us know if you would like to suggest other outcomes for consideration.

The closing date for responses is Friday, 16 December 2011.

How to respond to 'Seeing it my way'

- Complete the enclosed response form and return it to us in the freepost envelope, or place in an envelope and simply address to: FREEPOST UK VISION STRATEGY. The postage has been paid, so there is no need to attach a stamp.
- If you wish to give us your feedback over the telephone, you can call Stephanie Village at the National Blind Children's Society on 01278 764 771.
- Complete the online survey at www.vision2020uk.org.uk/ukvisionstrategy
- Contact Visionary on 01777 705 299 or email sue.ferguson@visionary.org.uk to find out if a local society in your area is holding a focus group about 'Seeing it my way' that you can attend and participate in.

This document is also available in braille, audio and easy read formats, as well as electronically and can be requested by contacting Stephanie Village at the National Blind Children's Society on 01278 764 771, or by visiting the Vision 2020UK website at www.vision2020uk.org.uk/ukvisionstrategy



Appendix 1

Background and case for change

Services are already failing to meet current needs and demand will increase in the very near future. Demographic forecasts show that by 2021, 40 per cent of the population will be over the age of 50.

A significant proportion of sight loss is related to age and one in eight of people over 75 and one in three of people over 90 have serious sight loss (Evans JR et al. British Journal of Ophthalmology 2002). Diabetes and hence diabetic retinopathy among children and young adults is also increasing. These findings mean that there will be an increasing need for sight loss services in the years to come and it is important that those services are delivered with appropriate quality safeguards.

We know that early detection is crucial to the successful treatment of many eye conditions. However, there has been a failure to invest in early detection and treatment of eye disease leading to increased spending on health, social care, education and training to support people in the later stages of eye disease. Many children are not receiving the eye care they need and could therefore be disadvantaged in fulfilling their potential.

There is inconsistent integration of primary and secondary eye care services and a lack of awareness among the general public and among some health, social care and educational professionals. Links between health, education and social care services can often be poor, leading to a failure to support individuals and families adequately.

Structured or formal emotional support, including counselling is almost non-existent, despite the acknowledged trauma of sight loss. This can mean that people will be slower to regain confidence and learn new skills.

Availability of information varies considerably. This prevents individuals from exercising choice and control. Social care assessments can fail to identify the serious consequences of being blind or partially sighted and people then can receive little or no support. There is also a significant shortfall in the number of qualified rehabilitation workers to work with adults and children.

Three out of four blind or partially sighted older people live in poverty or on its margins (Unseen RNIB 2004) and only 34 per cent of blind and partially sighted people are in employment (Douglas et al. Network 1000. Victar/Vision 2020 UK 2006).

Many people who are blind or partially sighted never go out because the social care system does not meet their needs. Cost of transport and access difficulties reduces mobility. Public buildings are often not designed to be accessible, leading to the isolation and social exclusion of blind and partially sighted people.

Services are often uncoordinated leading to waste of resources both in terms of money and time. At a time when all resources are stretched and strained, there has never been more willingness for organisations to collaborate rather than compete to ensure better outcomes for blind and partially sighted people.

Appendix 2

Recent initiatives

Initiatives on eye health and sight loss services over recent years have included:

- A Sharper Focus – Social Services Inspectorate 1998
- Sensing Progress – Scottish Office 1998
- Improving Lives, Priorities in Health and Social Care for Blind and Partially Sighted People – The Improving Lives Coalition 2001
- Progress in Sight – Association of Directors of Social Services 2002
- Community Care Services for People with a Sensory Impairment Action Plan – Scottish Executive 2003/2004
- Challenge and Change – an inspection of Social Work and related services for adults with sensory loss – Social Services Inspectorate, Northern Ireland – 2005
- Visual Impairment Benchmarking Study Summary – Wales Council for the Blind 2006
- Good Practice in Sight – RNIB 2008
- Improving Eye Health Services – World Class Commissioning 2009
- You and Your Vision – UK Vision Strategy 2010

Most of these reports and publications have been produced by one of the bodies working in sight loss, albeit with consultation. This framework will be different because it is developed from what blind and partially sighted people have told us and because it will represent a consensus across the whole spectrum of organisations and agencies providing sight loss and vision services.

Appendix 3

About the UK Vision Strategy

The UK Vision Strategy, launched in 2008, has made great strides in encouraging partnership working and innovative practice in vision and sight loss services. The strategy set out three outcomes, which have remained the foundation of much of the work that has taken place.

- 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

Further information on the UK Vision Strategy can be found at:
www.vision2020uk.org.uk/ukvisionstrategy

‘Seeing it my way’ steering group

The UK Vision Strategy is uniting all those in the UK, individuals and organisations, who want to take action on issues relating to eye health and sight loss. Partners of the UK Vision Strategy and members of the ‘Seeing it my way’ steering group include:

- Action for Blind People, Miriam Martin, Director of Development
- Guide Dogs, Carl Freeman, Health and Social Care Policy Manager
- London Borough of Barking and Dagenham, Bill Brittain, Group Manager Intensive Support
- RNIB, Barbara McLaughlan, Eye Health and Social Care Campaigns Manager
- RNIB, Philippa Simkiss, Head of Evidence and Service Impact
- Social Care Association, Rehabilitation Worker Consultative Network, Simon Labbett
- UK Vision Strategy, Deborah Hamlin, Interim Senior Project Manager
- UK Vision Strategy, Anita Lightstone, Programme Director
- Visionary, Angela Tinker, Chief Executive





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