

## **See Hear: A strategic framework for meeting the needs of people with a sensory impairment in Scotland**

### **A response from the Scottish Vision Strategy Advisory Group**

The Scottish Vision Strategy Advisory Group (SVSAG) welcomes the continued attention by the Scottish Government being given to the eye care sector, however, we would like to stress that there is a need for continuity with other initiatives already in existence and our priority for improved service quality expectations. This paper outlines a number of issues which the SVSAG would like to highlight for inclusion in the See Hear strategic framework.

### **UK Vision Strategy**

The UK Vision Strategy was launched in 2008 in response to the World Health Assembly Resolution of 2003 which urged the development and implementation plans to tackle visual impairment, now known as VISION 2020 plans. It reflects the objectives of the World Health Organisation's action plan as well as wider policies, including United Nations Conventions and World Health Organisation's initiatives on the Rights of Children and persons with disabilities.

Following a consultation with over 650 organisations and individuals, the UK Vision Strategy was developed and sets a strategic framework for improvement to the UK's eye health and outcomes for people with sight loss. The strategy is a cross sector initiative, uniting all those in the UK who want to take action on issues relating to vision.

The UK Vision Strategy seeks a major transformation in the UK's eye health, eye care and sight loss services. A determined and cross sector approach will make that change a reality. The strategy is a VISION 2020 initiative led by the Royal National Institute of Blind people.

### **Scottish Vision Strategy**

The Scottish Government has pledged its support for the resolution, and the Scottish Parliament's Cross Party Group on Visual Impairment unanimously agreed that Scotland should have its own implementation plan. This reflects Scotland's devolved responsibilities and builds upon our already impressive investment in eye care and service provision.

The strategy has been developed by a wide alliance of statutory health and social care bodies, voluntary organisations, eye health professionals, government representatives and service users. It builds upon the Review of Eyecare Services published by the Scottish

Government in 2006 and the wider Health and Social Care policy framework to seek the following strategic objectives:

- To improve the eye health of the people of Scotland.
- To eliminate avoidable sight loss and deliver excellent support to those with a visual impairment.
- To enhance the inclusion, participation and independence of blind and partially sighted people.

It maps out the challenges for Health, Social Care and Government in improving eye care services. It recognises that it must engage with all of the key stakeholders to be effective, and that there needs to be a greater focus on prevention and on empowerment.

**The Scottish Vision Strategy was fully endorsed by the Minister for Public Health at that time, Shona Robinson;**

“I am delighted to endorse the Scottish Vision Strategy and welcome the commitment and willingness of everyone involved to continue to work together to achieve its aims.... Scotland has already made tremendous strides in improving eye care, establishing a number of world class services....Developing the Scottish Vision Strategy has involved an impressive example of cross-sector working....I am confident that by working together partners in Scotland can achieve vital improvements in eye care health, enabling people to take up opportunities and meet the challenges the 21st century brings. The Scottish Government looks forward to playing its part in realising the aspirations and ambitions advocated in the Strategy”

The Scottish Vision Strategy has since been reviewed (‘Success in Sight’ 2011) to examine in detail the progress made to date and re-focus the future steps to be taken within the eyecare sector in Scotland. **The Minister for Public Health, Michael Matheson fully endorsed the review;**

“This updated strategy reflects some of the tremendous achievements over the last 4 years, including a Scottish Government investment of £6.6m over a 10-year period, which will enable optometrists to electronically refer patients to Hospital Eye Services, a commitment to devise a Scottish Sensory Impairment Strategy, and the development of integrated care networks and pathways...the Scottish Government is keen that the excellent working partnership across the eye care sector and with other key stakeholders continues, and that the recommendations contained within this Review are fully explored.

Ultimately, we also look forward to realising the ambition of eliminating avoidable sight loss by 2020”

The importance of the Scottish Vision Strategy, its links to the other UK countries and World Wide initiatives must be reflected within a sensory impairment strategy. There are similarities between the Scottish Vision Strategy and what is set to become a sensory impairment strategy. Both strategies complement each other and should work together towards their shared goal of reducing unnecessary sight loss and sensory impairment across Scotland.

### **1. Practise expectations and standards**

A sensory strategy should be required to set out both the practise expectations and standards which must be met to provide a ‘seamless provision of care’ both locally and nationally. This is not currently set out in the See Hear strategic framework.

#### **‘Seeing it my way’**

‘Seeing it my way’ is an initiative taking place in each part of the UK, which sets out a range of outcomes which blind and partially sighted people have said are important to them. The purpose and aims of ‘Seeing it my way’ is to ensure that blind and partially sighted people will have access to the same range of information, practical advice and support regardless of where they live in the UK.

This is a key document which has received particularly strong support across the eye care sector in Scotland. It is beginning to be used by local authorities and local societies as a basis for their service provision and their standards.

It has been developed by blind and partially sighted people themselves and therefore critically reflects what they both want and need. With the key aim of the See Hear strategic framework to ensure that people with a sensory impairment receive a ‘seamless provision of care and support’ across Scotland and locally and to ensure that sensory services are person centred and outcome based, ‘Seeing it my way’ needs to be given careful consideration as a framework of what service users can expect from their services.

([www.vision2020uk.org.uk/ukvisionstrategy/seeing-it-my-way](http://www.vision2020uk.org.uk/ukvisionstrategy/seeing-it-my-way))

### **2. Education**

Children with a sensory impairment are unnecessarily failing and many families are not receiving the support they require. The role of Education as a partner in any discussions around sensory impairment and children is missed completely within the See Hear strategic framework. If this is to be a 'cradle to grave' approach, then Education and their services need to be embedded throughout any strategy. Any problems which are raised in childhood and not addressed will follow children into adulthood.

Habilitation needs to be clearly defined – this is currently missed and there is very patchy provision with some Local Authorities not providing this service at all and in others, it is delivered by adults with no training in the developmental needs of children and young people. Standards, consistency and emphasis are needed.

In addition, a lack of access to technology and learning creates major difficulties for children and young people which continue into adulthood.

A number of organisations who support Children and Young People living with sight loss such as SAVIE (the professional forum for Qualified Teachers of the Visually Impaired), the Scottish Sensory Centre and the Managed Clinical Network on Children (VINCYP) are also responding to this consultation.

### **3. Low vision**

Low vision is not acknowledged within the See Hear strategic framework and yet it impacts upon an estimated 150,000 people per year. All too often, people are not sign-posted to the various services provided through optometrists, orthoptists, statutory and voluntary organisations.

It is recommended that the sensory strategy explores the role of low vision and how the strategy can address the issues surrounding this.

### **4. Complex needs**

Whilst there is some mention within the See Hear strategic framework around 'hidden sight loss' and learning disability, this needs to be embedded throughout the strategy, particularly around prevalence, access to services, the training which will be required to screen and support this service user and the need for specific pathways that reflect service access requirements.

### **5. Shared Care**

There are two approaches for shared care:

1. Carers Strategy Scotland (2010-2015) outlines that the Scottish Government and local authorities are determined to ensure that carers are supported to manage their caring responsibilities with confidence, in good health and to have a life of their own outside of caring. Recognising carers as equal partners and acknowledging their expertise is emphasised within the Carers Strategy – there is no direct link within the See Hear strategic framework. Further emphasis and detail of how this should be developed, needs to be included within the strategy.
2. Shared care has also been developed by professional services where patient care is transferred to the community services. For example, glaucoma services which have in some localities been successfully developed between Optometry and Ophthalmology to deliver informed community support and treatment for this condition. Given the capacity and demand issues which exist within hospital eye care services and capacity within Optometry practises to develop these initiatives further, this approach to joint working needs to be explored within the sensory impairment strategy.

## **6. One Stop Shop**

This is mentioned twice within the See Hear strategic framework and yet there is no explanation as to what this is, should be or whether guidance will be issued around this. The sensory strategy needs to establish precisely what is being prescribed and how, why and on what evidence base has this model been selected as the way forward for service delivery.

## **7. Ethnic Minorities**

Ethnic minorities are not mentioned within the See Hear strategic framework. We know that there are particular EM groups who have a higher risk of experiencing sensory loss. We also know that there are major communication (language) and accessibility issues and differing cultures and approaches to health and social care. Again, this group needs to be embedded throughout any National strategy to ensure that we develop a joint sensory service which can both manage and meet their specific needs (particularly in relation to information provision, awareness, engagement and care pathways)

## **8. Integration of EyeCare services**

This groundbreaking Scottish Government initiative is not acknowledged within the See Hear strategic framework. The roll out of the implementation of electronic patient referrals from optometrists to hospital eye services is currently underway.

This was launched in September 2010 when the Scottish Government announced the investment of £6.6 million over a 10 year period for the project. The key benefits of electronic referral were seen to be:

- Reduction in the time from referral to treatment
- Allocation of patient to the correct clinic at first hospital visit
- Reduction in unscheduled attendances
- Identification of patients suitable for community care

The overarching aim is to deliver 95% of referrals from optometrists to hospital eye services by April 2014. In addition, 95% of optometry payment claims should be submitted electronically by this date.

This is a unique initiative to Scotland and its success which has been peer reviewed, has been huge. Moreover, it is currently being explored and assessed for feasibility within Wales. A sensory impairment strategy must consider whether this can be developed to encompass sensory impairment and what impact this could potentially have.

## **9. Transitions**

Transitions needs greater emphasis within the See Hear strategic framework, it is an area where many people across the sensory impairment spectrum fall through the gaps. Transitions need to be considered more widely as well, so not just at the key or obvious stages, but at all the important or key stages in an individual's journey.

## **10. Finance**

In 2010, the report 'Cost of Sight Loss: Scotland' estimated that the annual cost of sight loss was a minimum of £17,646 per person. Of this, £5,451 were costs to the public sector. With a general medical admission costing £1,790 in the preceding year, the cost was estimated as being equivalent to ten hospital admissions per year.

Wider exploration needs to be given to two things; the prevalence predictions for sensory impairment over the next ten years and the capacity of funding for service provision to meet this and secondly, in line with the Scottish Governments commitment to both prevention and

anticipatory care, the cost benefit of early intervention and differing measures.

## **11. Emotional support, Vision Support Services and Peer Support**

There is compelling evidence to suggest that acquired sight loss negatively impacts on emotional well-being. Every day in Scotland, ten people begin to lose their sight. But only one in six will be offered support and counselling. Yet without support in coming to terms with sight loss, people find it very difficult to develop positive coping strategies. They can rapidly lose confidence, leading to social isolation, and experience feelings of depression, anger and confusion. The importance of emotional support and early intervention at the point of diagnosis has been outlined in previous reviews, including the Review of Community EyeCare Services in 2006, and must be reflected within a sensory strategy.

Work is underway across Scotland to establish a network of local Vision Support Services. These will offer newly diagnosed people support and act as a signpost to other services available to help them, both emotionally and practically, in adjusting to their new circumstances. They can also advise on the aids and adjustments that can make life easier, help people to retain their job or retrain for new work, and explain what financial benefits are available. Vision Support Services are currently in operation at a number of hospital-based locations throughout Scotland. These are primarily for people newly diagnosed with sight loss.

Joint sensory services delivered by the voluntary visual and hearing loss organisations, in partnership with health boards and local authorities offer more practical help and assistance to people experiencing sight and/or hearing loss, such as advice and help on aids and equipment that can enhance people's independence

The See Hear strategic framework currently fails to fully recognise the importance of emotional support for those with a sensory impairment (particularly those who are newly diagnosed). It needs to be embedded throughout the strategy as a form of early intervention.

## **12. Audit of Sensory impairment & evidence of service planning**

A comprehensive needs assessment should be conducted across Scotland to determine what the numbers of people with sensory

impairment are. There needs to be a clear idea of the current service use and need across Scotland and locally, this will be the foundation for building the right local solutions. This exercise could yield irrefutable evidence and set a new standard for patient data collection.

Consideration also needs to be given to the role of the registration process for blind and partially sighted people. A register of those either blind or partially sighted is often used within the sight loss sector as a 'benchmark' for people living with sight loss in Scotland.

Registration is voluntary and while it provides access to a number of benefits and concessions there remain a large number of people who meet the criteria, but are not registered. Previous research undertaken by RNIB throughout the UK indicated that the number of people on registers is some 23 per cent of those eligible; in 2001 it was estimated to be under a third in Scotland<sup>i</sup>.

A major review, highlighting the urgent need to modernise the current registration process and ensure it was 'fit for purpose' in Scotland was conducted and submitted to the Scottish Government in 2012. The sensory strategy must explore the Review of Registration and the recommendations it set out. The review discusses modernising the registration process to a sensory 'notification' system, which builds upon the successful digital eye referral work underway by community Optometrists in Scotland.

### **13. Access to technology**

There is little discussion within the See Hear strategic framework about access to technology, particularly for those with a visual impairment. A critical issue for people with a sensory impairment is to ensure that they can fully participate in society and this involves all the various stages of digital access including initial access, continued training and development support.

Technology is an essential skill and benefit to visually impaired Children and Young People, enabling equality within schools and the workplace. It allows social interaction through social networking sites, facilitates improved educational achievement and progress. Young People who are more vulnerable need support to develop the IT skills necessary for enhanced inclusion in society.

### **14. Employability**

The See Hear strategic framework makes a brief reference towards those seeking work or engaged in work, but very little emphasis is given to the implications of sensory impairment after diagnosis and when someone moves away from health professionals. By not recognising the impact of sensory impairment on post 16 education and employability, the strategy critically misses the ability to transform the lives of a significant number of people

## **15. Accountability**

The See Hear strategic framework does not provide any information on Accountability and Governance for a sensory impairment strategy. Who will be responsible for actions, products, decisions, and policies including the administration, governance, and implementation within the scope of sensory impairment? And who will be obligated to report, explain and be answerable for resulting consequences, both successful and not? This needs to be explicit within the strategy to ensure that health, statutory and third sector organisations and service users and their families/carers can be confident that the strategy will be implemented and to the highest standard.

## **16. Conclusion**

The Scottish Vision Strategy Advisory Group (SVSAG) is in support of the broad aims of the sensory strategy. It is important that;

- a) The significance of the Scottish Vision Strategy within the World Health Organisations focus is recognised;
- b) The additional opportunities discussed in this response from the SVSAG are adopted;
- c) There is recognition that implementation of the sensory strategy will be critical.

The Scottish Vision Strategy Advisory Group is keen to play an active role in ensuring that the sensory strategy is implemented successfully across Scotland.

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<sup>i</sup> Scottish Government, 2010. Registered Blind and Partially Sighted Persons, Scotland. National Statistics for Scotland.