

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

### **A response from the Royal National Institute of Blind people, Scotland**

#### **RNIB Scotland**

RNIB Scotland is the leading charity working with blind and partially sighted people in Scotland, with a reach of approximately 43,000. As a membership organisation, we are dedicated to delivering person centred services assisting blind and partially sighted people across Scotland to secure their civil and welfare rights. We support children and adults with sight loss to live full and independent lives.

RNIB Scotland has consulted with our members and member representatives, service users, volunteers, staff and our partners. We have also conducted consultation events in collaboration with other organisations and partners across Scotland, including various Local Authorities and Health Boards.

With around 188,000 people living with significant sight loss across Scotland, we are privileged to provide a response for consideration in the See Hear: a strategic framework for people with sensory impairment in Scotland consultation process.

#### **1. Overall thoughts on the document**

RNIB Scotland welcomes the Scottish Government's focus upon the sensory impairment sector and the opportunity to build upon the continuous achievements made in the eye care sector in Scotland to date.

This is a period of continuous change and uncertainty. The Health and Social Care Integration Bill is currently progressing through the parliamentary process. It is critical that sensory impairment is not lost in the implementation of this strategy, but is comprehensively embedded.

The See Hear strategic framework is written in a positive light and makes common sense suggestions as to how we achieve a joint sensory approach. However, RNIB Scotland feels that the framework is written in quite general terms and would benefit from enhanced detail. In particular, we are also keen to highlight the need for continuity with other related policy initiatives and the need for improved preventative strategies, support for people living with sight loss and equality.

## **2. UK & Scottish 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.

### **Scottish Vision Strategy**

The Scottish Government has pledged its support for the World Health Assembly 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. Building upon the Scottish Government's policy framework, the original Scottish Vision Strategy was endorsed by Shona Robinson, MSP, the Minister for Public Health and by the current Minister Michael Matheson, MSP.

The refreshed strategy has the following objectives:

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

The importance of the Scottish Vision Strategy in relation to the World Health Organisation initiatives must be reflected within a sensory impairment strategy.

**Recommendation 1:** There are similarities between the objectives of 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, improving support and inclusion across Scotland.

### **3. 'Seeing it my way'**

‘Seeing it my way’ is a vision strategy initiative taking place across the UK, which sets out a range of person centred 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 eyecare sector in Scotland, including the Scottish Vision Strategy Steering Group (SVSAG), Scottish Council of Visual Impairment (SCOVI), Guide Dogs Scotland and other leading organisations in the eye care sector. Encouragingly, the principles of ‘Seeing it my way’ are beginning to be embedded in local authorities and local societies within Scotland.

It has been developed through extensive engagement by blind and partially sighted people from across Scotland and therefore critically reflects what they both want and need. With a 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.

During the work of the steering group, an adapted version ‘Seeing and Hearing it my way’<sup>i</sup> was proposed. Initial feedback has been positive from the deaf and hard of hearing organisations; it is recognised that further discussion and exploration of how this initiative would be adopted is required.

**Recommendation 2:** There is a unique window of opportunity to align the development of a sensory strategy with the implementation of ‘Seeing it my way’ and to contribute to a step-change in the way in which blind and partially sighted people access services.

<http://www.vision2020uk.org.uk/ukvisionstrategy/seeing-it-my-way>

#### **4. Policy context**

The See Hear strategic framework outlines a number of important strategies which currently exist within Scotland. What must be made more explicit is where a sensory impairment strategy sits within these, how we can learn from other national initiatives and how we can share expertise. A good example is where care pathways are discussed; will this model be included in other strategies? Sensory impairment needs to

be embedded in the Learning disability strategy, Falls strategy, Autism strategy and Dementia strategy to ensure that sensory impairment issues are part of mainstream assessments. Recent research into falls in England and Wales has highlighted the projecting number of falls related to visual impairment<sup>ii</sup>.

In addition, learning from other national initiatives, such as the Demonstrator sites which are part of the National Dementia strategy should be considered. One of the aims of the National Dementia Demonstrator Sites was to show how a whole system pathway redesign using the same or less resource can result in better care using a step-change approach by releasing resources from one part of the system to another. This has been successfully evidenced in the three pilot areas and would offer a practical way of implementing elements of the framework.

**Recommendation 3:** The sensory strategy must review the current policies already in existence and their relevance to sensory impairment. Shared learning and cross-over between strategies should be acknowledged and applied.

## **5. The importance of voluntary contributions**

It is outlined within the See Hear strategic framework that the responsibility of systems of care lies with the statutory agencies, but can be delivered across a wide range of agencies and settings, including the third sector. It is vitally important that the role of third and voluntary sector organisations is not lost within a sensory strategy. At the present time, a large number of local authorities have contracted out their services to the third sector, including Edinburgh and Lothian's, Aberdeen City, Fife and others, such as, Forth Valley have created partnership vehicles in collaboration with local authorities. Third sector and voluntary organisations bring a range of added value to service delivery and often provide a significant financial contribution in doing so. This must be reflected in the sensory strategy.

*"I support the flavour of the strategy as it gives you something to work to. Don't get hung up on rigidity...it will have to breathe and develop as time goes on. From the statutory provider point of view...the third sector have the expertise so use them rather than doing it yourself"* **Service User**

Whilst an audit of current spend across sensory impairment is a logical approach, in the context of the current and future scarcity of resources,

alongside the joining up of Health and Social Care in Scotland, robust requirements should be built into the sensory strategy to ensure that effective partnerships are maintained and further developed. There is a danger that any 'realignment of spend' could mean securing existing statutory services at the cost of the often invaluable local and community based services provided by the third and voluntary sector.

**Recommendation 4:** The sensory strategy needs to be explicit in how extensive the audit of current spend will be. The sensory strategy should also outline a framework of how this will be done and what the anticipated outcomes of this are. It should also take account of the important contribution of third sector organisations, both at a local and national level.

## **6. Early Intervention**

### **Free Eye Health Checks in Scotland**

In 2006, free eye health checks were introduced across Scotland. The basic eye examination was broadened to include a health assessment of a patient's whole visual system. The free service now available, enables everyone in Scotland to benefit from this service and allows access to eyecare that is appropriate to individuals needs in a setting as close to their home as possible. Optometry is the pivotal point of this service, working with ophthalmologists and orthoptists in hospital, and GPs and social workers in the community.

Although the See Hear strategic framework states that potentially 50% of sight loss is due to preventable or treatable causes, it does not mention the role of free eye health checks or the essential need for individuals to regularly attend their Opticians to monitor their eye health. We know that the quality of eye care in Scotland has improved since the introduction of free eye health checks, but there is a need to highlight that there is a much lower up-take of eye health checks by those in areas of deprivation and hard to reach groups<sup>iii</sup>. The role of the community based Optometrist is critical and should be reflected in the sensory strategy.

*"Point of diagnosis....spend to save"* **Service User**

### **Integration of EyeCare services**

This initiative is not acknowledged within the See Hear strategic framework. Work is continuing on the integration of eyecare services in

Scotland with the focus currently on the introduction of a process for electronic patient referral from optometrists to hospital eye services.

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 will 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 the success within the pilot areas has been astounding<sup>iv</sup>.

**Recommendation 5:** There are 1.8 million people going through Optometry services each year. The Scottish Government must build on the opportunities available through this unique initiative, not just for those with a sight loss, but also with other at risk groups, by maximising the GOS contract and the role of the community Optometrist.

A sensory impairment strategy must consider whether this can be developed to encompass sensory impairment and what impact this could potentially have.

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

There is compelling evidence to suggest that acquired sight loss negatively impacts on emotional well-being<sup>v</sup>. 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.

*“At the point of diagnosis, more responsibility needs to be taken. When you are told, everyone needs to understand their own condition. There was no department or individual, no information given – even though I was perfectly capable of*

*receiving it. It's about how people are and should be dealt with as individuals"* **Service user**

Work is underway across Scotland to establish a network of local Vision Support Services supported by health and social care, largely funded by the charitable sector. These will offer newly diagnosed people support and act as a signpost to other statutory and third sector 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. In Northern Ireland, a comprehensive approach has been rolled out by the Government and statutory health and social care providers covering every major hospital, with huge benefits.

Vision Support Services are currently in operation at a number of hospital-based locations throughout Scotland and proposals, albeit, unfunded, are in progress to extend this vital service to all parts of 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 additional 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

**Recommendation 6:** It is recommended the sensory strategy recognises the importance of emotional support for those with a sensory impairment (particularly those who are newly diagnosed). This critical issue must be funded along the lines of the Northern Ireland model and reflected and embedded throughout the strategy as a form of early intervention.

*"You are severely left wanted at the point of diagnosis – when you are told 'your condition is'. I was told over the phone that my sight loss was severe and I was eligible to be registered as blind. I was gobsmacked...shocked and honestly horrified. I had no idea what to do...not one clue. And it was I who had to instigate any kind of follow up. The business of joining up service and one stop shops clearly needs to be addressed in even the most basic manor"* **Service user**

## **8. 'One Stop Shop'**

This is mentioned twice within the See Hear strategic framework. It would be helpful if there was a Scottish Government review on the future of this service model. If it is to be adopted, then a sensory strategy

would need to be explicit in setting out the evidence base for this model and the best approach to implementation.

There is excellent evidence of joint working between the third sector and local authorities of this model having both value and impact. This model of service delivery can be very effective in improving service provision, and a sensory strategy should be supportive of this approach. It is a good means of generating and maintaining community involvement in improving the range and quality of services and achieving greater integration on the ground.

*“Compartmentalisation of the services – there needs to be an overview of bringing everything together so that the service user gets the best of what’s available” **Service user***

**Recommendation 7:** A Scottish Government review should be conducted to determine the future of this service model and outline the key evidence base for delivery.

## **9. 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 by optometrists, orthoptists, statutory and voluntary organisations.

**Recommendation 8:** It is recommended that the sensory strategy explores the role of low vision and how the strategy can address the issues surrounding this.

## **10. ‘Hidden’ sensory loss and complex needs**

Despite an ever-increasing focus on regulatory standards in education, health and social care, research shows that sight loss often goes undetected amongst children, adults and older people with complex needs and that provision does not take account of needs associated with sight loss.

“Hidden sight loss” is a term used to describe when vision is not the presenting condition or disability. Consequently vision issues may be “masked” by the primary condition or disability. The term is also used where standard services are unable to engage with “hard to reach” groups, including ethnic minority communities (discussed in more detail in section 11) and low income communities. In Scotland hidden sight loss represents a considerable challenge to managers, planners and practitioners alike.

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 a specific pathway.

It is critical that a sensory impairment strategy acknowledges that 'hidden sensory losses or 'hidden need' are explored. Many people with certain conditions are labelled as having conditions which challenge services as a result of undetected and unmanaged sight loss. Work needs to be carried out to differentiate between potential visual related behaviours and behaviours which are associated other conditions, such as, Dementia.

There is no baseline audit or information for the following;

### **1. Learning disabilities and sensory impairment**

- There are estimated to be over one million adults aged 20 and over in the UK with a learning disability.
- People with learning disabilities are ten times more likely to have serious sight problems than other people. People with severe or profound learning disabilities are most likely to have sight problems.
- People with learning disabilities may not know they have a sight problem and may not be able to tell people. Many people who know a person with a learning disability think that they can see perfectly well.
- Six in ten people with learning disabilities need glasses and often need support to get used to them.
- People with learning disabilities need to have an eye test every two years, sometimes more often. Regular eye tests and wearing glasses helps people stay healthy and get the most from life.

### **2. Stroke and sensory impairment**

We know that 61% of people who have suffered a stroke have visual problems upon admission. 22% of these people will have persistent visual problems at 90 days post-stroke. Protocols and management plans are required to ensure that appropriate and consistent assessment, treatment and referral of people who have suffered a stroke who will have potential sensory loss takes place.

Recent work undertaken by the Forth Valley Sensory Centre (FVSC), founded through the 'one-stop-shop' initiative, highlighted the huge under reporting of people with a stroke and sight loss. The initiative has seen a major increase in the numbers of referrals made to the FVSC of those who have suffered a stroke and also have a visual defect; the number of referrals per year was 2 people and the initiative has seen an increase to 10 people over a 3-4 month period, which equates to a minimum of 40 people per year. This is a significant increase and emphasises the need to ensure those suffering sight problems following stroke are identified and supported appropriately.

### **3. Dementia and sensory impairment**

It is estimated that there are up to 9000 people living with sight loss and dementia in Scotland. People with dementia, the condition that can erode memory and mental capability, often suffer sight loss that goes undetected. The problem is compounded by the fact that they are often unable to communicate it while their carers and health workers attribute any problems to their mental condition.

Those with dementia and sensory loss have increased levels of; isolation, risk of falls, mis-perceptions, mis-identification and visual deficiencies. Some unusual behaviour may simply be a reaction to sight loss or attempts to make the most of useful vision. In many cases, carers and families may notice the person they care for is becoming withdrawn or uncommunicative, confused and disorientated or being clumsy or falling more. Increasingly, people may hold things up close, or are startled by noises or people approaching. Whilst some of these issues may be due to a person's dementia, vision loss can also be a major factor and therefore vision must be checked to ensure that the correct diagnosis is made.

### **4. Mental Health and sensory impairment**

Sight loss has a profound impact on well-being. It can shorten life, increase the risk of other conditions, restrict social participation and independence and impair physical and mental health.

Sight loss can also cause depression. Various studies which have aimed to determine the prevalence of depression and its impact on those with a sight loss, have found that the estimated risk of depression is 3.5 times higher for those with a sight loss than those without. A range of mental health challenges can be experienced by people with sight loss, including: anxiety, depression and social withdrawal. Distress and anxiety are found to be experienced particularly during periods of

transition, for example, from school to work and at the point of onset of impairment where loss is not congenital.

**Recommendation 9:** There is a need for early intervention for patients with a sudden onset of sight loss, to avoid the development of depression. The sensory strategy must outline early intervention strategies and ensure that it links in closely with the National Mental Health Strategy.

## **5. Autism and sensory impairment**

Although evidence of the dual disability of visual impairment and autism is low, there is little doubt that sight loss has a very high impact on those concerned, as well as their families and those who provide them with services. Unfortunately, the needs of people who have both visual impairment and Autistic Spectrum Disorder (ASD) are not well understood. There are few publications which specifically address the needs of this group.

People with ASD will experience a range of ocular pathology (glaucoma, age-related macular degeneration, cataracts and uncorrected refractive error) some of which may be directly related to ASD and some will be a natural cause of the ageing process. Unless managed properly, all can be a source of severe visual impairment. Some of these difficulties are significant and in many cases exist unidentified. People with ASD may also experience a range of eye conditions.

In addition to the exclusion experienced by those with sight loss, people with ASD are often further disadvantaged by limited knowledge and understanding on the part of professionals and carers. Often an individual's abilities or behaviours are attributed to other causalities when in fact the causal associations with sight problems are under recognised. The subsequent loss of personal control and dignity is often the end result of inadequate care and support which limit the opportunities for people with ASD to realise their full potential, retain their independence and stay safe.

Without a sense of the numbers we are currently working with and the numbers we should be working with, it will be almost impossible to measure the successes or deficits of an integrated approach for all people who have a sensory impairment.

**Recommendation 10:** In addition to the recommended screening outlined in the See Hear strategic framework, the sensory strategy should ensure that a mandatory and monitored formal sensory assessment (as part of all current community care assessments) for

people with a learning disability, stroke, dementia, autism and mental health occurs.

## **11. 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.

- The Pakistani population have a prevalence of diabetes, with a corresponding increase in diabetic retinopathy, which is about 3-4 times that of the white population
- They also appear to be contracting the complications associated with the disease at an earlier age and present with more aggressive symptoms
- The West African population have a prevalence of glaucoma which is 2-3 times that of the white population

*“I would support the reference to BME issues....I support awareness raising and think that a lot of the Community Engagement Project learning (Glasgow based project) thus far should inform any response and strategy” GP*

Monies from the Review of EyeCare services in Scotland allowed some exploration around barriers, accessibility and engagement with ethnic minority groups, however the investment through these funding streams needs to be increased and continued. There is a lot of evidence to suggest that those from ethnic minority groups access mainstream services far less easily or frequently than the indigenous population. The barriers and difficulties around this are more than providing accessible information. Current services need to re-focus their approach to making their sensory services accessible, approachable and relevant to ethnic minority communities.

**Recommendation 11:** Ethnic minority communities need to be embedded throughout the sensory strategy to ensure that sensory services across Scotland can both manage and have the flexibility to meet their specific needs.

### **Current practise:**

Currently, there are two models of engaging with ethnic minority communities which are working particularly well; The Glasgow Eye Health Community Engagement Project and the Edinburgh and Lothian's Joint Sensory Project, one third of which focuses specifically on engaging with ethnic minority communities. Both models have

delivered successful eye health awareness and engagement across ethnic minority communities in Glasgow and Edinburgh and should be reflected within a sensory strategy, acknowledging that good practise does exist.

**Recommendation 12:** The sensory strategy should include and share areas of best practise, where current accessibility of information resources for community engagement and out-reach services with ethnic minority communities already exists.

A response to the See Hear strategic framework has also been provided by Dr. Kevin Fellows (GP) as acting Chair of the RNIB Community Engagement Project Advisory Group. This response will give a more extensive view on how the sensory strategy can meet the needs of those from ethnic minority communities with sight loss.

## **12. Carers**

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.

**Recommendation 13:** There is currently no link between the Carers Strategy and the See Hear strategic framework, and links need to be made between the two to ensure shared knowledge. The See Hear strategic framework needs to recognise the role of carers as equal partners, through acknowledging their expertise and understanding of sight loss. Further emphasis and detail of how this should be developed needs to be included within the sensory strategy.

## **13. Volunteers**

RNIB Scotland currently deploys approximately 700 volunteers, providing thousands of hours of service delivery and support. Across Scotland, it is understood that the numbers of volunteers involved in support provision will be at the very least double this number. This is a huge resource for service provision. A good example is Action on Hearing losses 'Hear to Help' project, which is run solely by volunteers and is incredibly successful.

**Recommendation 14:** The sensory strategy should formally recognise the role of volunteers as a key resource in service delivery for those with a sensory impairment and the knowledge and expertise they can bring with them. They provide a huge opportunity for sensory services to expand their current reach.

## 14. Standards

We need to emphasise that standards are required to provide a benchmark of good practise across Scotland. This is important for service users and service providers to know what is expected of a high quality service.

**Recommendation 15:** The sensory strategy needs to set out clearly what standards will be implemented to ensure there is a seamless provision of care locally and across Scotland. There also needs to be more detail of how this could be tied into other standards which already exist and who will monitor the progress against these standards.

*“If people ask you questions, you tell them your condition and then you are passed on...the standards are all different and that’s where the training comes in”* **Service user**

## 15. Accountability

The See Hear strategic framework does not provide any information on Accountability and Governance for a sensory impairment strategy. The sensory strategy needs to state who will be responsible for actions, decisions, and policies including the administration, governance, and implementation within the scope of sensory impairment. It also needs to state who will be obligated to report, explain and will 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.

**Recommendation 16:** The Scottish Government must outline clearly who will be responsible for monitoring the implementation of a sensory strategy to ensure consistency of service delivery across Scotland.

There should be a detailed implementation plan developed to set out the key milestones and timescales to ensure that a sensory strategy was adopted and implemented. This plan would also have to reviewed, with feedback on progress provided. There is a good opportunity for Cross Party Groups to have a key role in the reporting of progress in this process.

## 16. 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 are costs to the public sector. With a general medical admission costing £1,790 in the preceding year, the cost was estimated as being roughly equivalent to ten hospital admissions per year.

**Recommendation 17:** 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.

*“Recommendation 1 is around an audit of service spend, where it is currently spent, but there are gaps between what is spent and what people need. Will the audit pick up on that? Councils don’t have the money”* **Service user**

There have been a number of National Strategies introduced in Scotland over the last few years, such as, the National Dementia Strategy and National Autism Strategy, which have had significantly higher investment and resources allocated than is set out for the sensory impairment strategy.

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

We need to know who we are working for and with.

**Recommendation 18:** The Scottish Government should conduct a comprehensive needs assessment across Scotland to determine what the numbers of people with sensory impairment are.

For a sensory impairment strategy to be developed and for local areas and services to respond effectively to this, there is a real need to be clear about the current service use and need across Scotland and locally; this will be the foundation for building the right local solutions and could yield irrefutable evidence, setting a new standard for patient data collection.

*“We need to know who exists before we can develop our services to meet their needs. Who will do this?”* **Service user**

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>vi</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.

**Recommendation 19:** 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.

## **18. Shared care - Demand and Capacity**

There are significant concerns regarding demand for ophthalmology care within Scotland that is rapidly out-stripping capacity. One basic problem is that we remain uncertain about the available capacity to treat patients within the hospital eye service within Scotland. The demand is easier to ascertain, although there have been concerns raised about lack of accurate data regarding follow-up patients' needs for appointments.

This problem is being explored by the Demand and Capacity Working Group, but it is clear that the number of regular "waiting list initiative" clinics, treatment sessions and theatre lists being carried out that there is an under-capacity which may remain unidentified. Year on year, increasing numbers of patients are referred into the hospital eye service – last year saw approximately a 6% increase. Also, patients are requiring chronic care for conditions that were untreatable previously, such as age related macular degeneration and diabetic macular oedema. These treatments are hugely beneficial to the community and the population at large indicated by a commensurate reduction in blind and partially sighted registrations being recorded. They do, however, require resource and manpower to be delivered.

**Recommendation 19:** The sensory strategy must explore and identify methods to optimise or increase capacity for care, but it is essential that funding is not removed from the hospital eye service as the demands on increasing referrals and chronic care are certain to outstrip the transfer of conditions into the community. The overall cost and value of changes

in patterns of care also require close attention as, within ophthalmology, these have not been well researched or audited.

## **19. Rehabilitation**

Rehabilitation is a continuum of enabling interventions. These may include early anticipatory interventions, or targeted preventative work such as falls and fracture prevention. It also includes assessment, diagnosis and enablement through specific treatment, as well as support for self management and symptom management of sight loss. It always involves maintenance or recovery of function including social participation and ability to work.

Whilst there has been a move by the Scottish Government to fund some modular courses for rehabilitation workers, the See Hear strategic framework does not outline the essential need for this role or the importance which the role of rehabilitation can have in assisting people with significant sight loss to live full and independent lives. With the projected figures of an increase in the ageing population and the associated increase in sensory impairment alongside this, there will be a far greater demand for future rehabilitation interventions.

**Recommendation 20:** To ensure that we are able to meet the demand which will be required by rehabilitation services in the future, the Scottish Government should conduct a comprehensive review to determine the current numbers of rehabilitation workers in Scotland and how this can be increased.

## **20. Inclusive Society**

A sensory strategy should acknowledge the importance of creating an inclusive society for people with a sensory impairment. This will include reflecting on community based services, employment and training opportunities, civic engagement, access to leisure and sport and transport services.

*“People are unaware of what is there – I do use the library and have had some really good experiences. Audio books are widely available and downloadable....I have no knowledge of any other services...I don’t know what I can use or what I am entitled to”*

**Service user**

## **21. Accessible information**

Access to information that is accessible for blind and partially sighted people is essential so that they can make informed decisions and not

feel isolated due to communication barriers. Despite the Equality Act 2000, blind and partially sighted people are still experiencing difficulties in accessing accessible information to allow them to make informed decisions, get vital information, and they are excluded from social activities, such as, reading due to lack of unabridged audio books.

The Patients Rights (Scotland) Act, 2011 aimed to improve patients' experiences of using health services and to support people to become more involved in their health and health care. From April 2012, the act enabled patients to access health care which considers their needs, consider what would be of optimum benefit to them, encourage them to take part in decisions about their health and wellbeing, and provide information and support for them to do so. A key aspect of this Act outlined the provision of health information in a proactive manner in a way which was accessible to each individual patient.

**Recommendation 21:** With this Act in place, health information provided across the NHS should be available accessibly and therefore the sensory strategy must both acknowledge this legislation and the learning from this, which could potentially be applied across all statutory and third sector agencies.

The sensory strategy should also include an agreed set of standards for accessibility of information which all statutory and third sector organisations should adopt.

In addition to this, during our consultation events with service users and members, numerous people felt that the See Hear strategic framework was not written in 'plain' language and had it been, it would have been much easier to understand and respond to.

*“The consultation needs to be in ‘normal’ or accessible language so that we can understand what’s a foot and feed in properly”*  
**Service User**

## **22. Children and young people**

### **Education**

In Scotland, around 170 children and young people have sight loss each year, with a total of over 2000 people. Children with a sensory impairment are unnecessarily failing in both education and employment, and increasingly face exclusion from the digital world. Many families are not receiving the support they require. Education and their vital involvement as a 'partner' in any discussions around sensory impairment

and children are missed completely within the See Hear strategic framework.

*“Should we be focusing upon younger people with interventions and not older people? The earlier we do things, the better effective it is”* **Service User**

**Recommendation 22:** In line with the Scottish Governments policies on prevention and anticipatory care, the exclusion which children and young people with a sensory impairment endure, needs to be addressed within a sensory strategy. Any problems which are raised in childhood and which are not addressed will follow children into adulthood. With a ‘cradle to grave’ approach, Education and their services need to be embedded throughout any strategy.

## **Habilitation**

Children with visual impairments need specialist help to develop daily living skills and independent travel; this differs markedly from adult rehabilitation. Children who are born without sight have particular developmental requirements when learning to get about independently and trained specialists are essential to the appropriate delivery of those skills. The critical role of habilitation is not reflected within the See Hear strategic framework.

**Recommendation 23:** The sensory strategy must ensure that habilitation is both included and defined. There is very patchy provision with many local authorities not providing this service at all and in others, it is delivered by a workforce who are not trained to work with children and young people and therefore do not have the appropriate or necessary skills to work with children and young people or their parents. Standards, consistency and emphasis are needed.

**A range of other issues relating to children and young people specifically also need to be explored and included within a sensory strategy including;**

- **Independent living skills**

A visually impaired child must be nurtured positively and supported to develop personal independence. Skills development must include the ability to perform the routine activities of daily living, such as washing and dressing; social and communication skills; organisational skills; and good health and wellbeing. All independent living training should be delivered as part of a child-centred habilitation programme.

- **Mobility**

To live independent lives and to ensure social inclusion all visually impaired children and young people should receive mobility input as part of a child-centred habilitation programme. Skills could include; how to use a long cane effectively; how to plan and follow a route within school or in the local area; how to use public transport; lessons suggesting strategies for staying safe when crossing roads and when out and about.

- **Lack of confidence**

Visually impaired children and young people face significant challenges to social inclusion and acceptance. Limited independence and opportunities can lead to social isolation and affect personal self-esteem and confidence, To overcome this, families need support to nurture their children with a positive 'can do' attitude to sight loss. Emotional and practical support should be provided and community facilities should be accessible to all. Emotional support and guidance is currently unavailable to children and young people living with sight loss in Scotland.

- **Educational attainment**

Recent research from the Scottish Sensory Centre (2013) demonstrated that visually impaired children and young people under-perform academically when compared with sighted and hearing impaired peers. Local authorities need to safeguard the specialist input provided by Qualified Teachers of the Visually Impaired to ensure that children and young people receive appropriate individualised intensive support to access the curriculum. Assistive technology, which is vital to the visually impaired learner, should be able to access school networks, wifi and printers. This is currently not happening in many local authorities; who are not fully compliant with Equality legislation. A stronger working partnership through GIRFEC (Getting it Right for Every Child) should improve child-centred delivery. However, greater parental involvement in planning and support should be facilitated. This will enable a more holistic approach to child development.

- **CVISTA (Children's Visual Impairment Services Tayside Agencies)**

This model of multi-professional collaboration is regarded as the gold standard for support to visually impaired children in Scotland. It involves joint assessment of functional vision; planning and service delivery with the individual visual needs of the child at the centre.

- **Role of the new Managed Clinical Network**

A Managed Clinical Network has been established to improve visual impairment services for children known as VINCP (Visual Impairment Network for Visually Impaired Children). Its aims are to develop a structure within health, in collaboration with other agencies, which would develop a care pathway for children with visual impairment. This would facilitate the identification of children, help ensure their appropriate assessment and guide clinical management and follow up; it would also improve data collection to allow clinical audit and service planning; and would work with partners to ensure appropriate and timeous referral to support agencies within education, social work and the third sector.

The MCN will advise on clinical standards, protocols and pathways; which would in turn assist professionals as well as informing and empowering children and parents to manage their care more effectively.

In addition, RNIB Scotland hopes that this network will improve the early intervention support available to families at the earliest stage of the sight loss journey. This should include emotional and practical support as well as signposting to relevant statutory and voluntary agencies.

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.

**Recommendation 24:** The MCN should be used as one of the main vehicles for implementing the sensory strategy.

### **23. Transitions**

Transitions are an area where many people across the sensory impairment spectrum fall through the gaps.

It is a particularly difficult area for children and parents, as 'joining up' services is difficult. With a cradle to grave agenda, a sensory strategy needs to outline what will be done to smooth, the often abrupt stop to education and paediatric services and the introduction to accessing adult services.

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 educations and employability, it is critically missing the ability to change the lives of a significant number of people (figures around the number who have to leave employment due to sensory impairment and those who are struggling to find employment).

RNIB Scotland continues to emphasise the need to improve the employment prospects of blind and partially sighted young people.

The Certificate in Work Readiness has been discussed as a possible fit with RNIB Scotland's intern scheme, although there has been a difficulty in identifying a suitable host for the SQA element, which has created a stumbling block to RNIB Scotland's participation. This is currently being piloted and is being rolled out across Scotland. There is a possibility that Skills Development Scotland will look at the certificate's potential for its use with people with sensory loss.

Community Jobs Scotland are currently well used by RNIB Scotland in the three social firm cafes and elsewhere within RNIB Scotland and to date we have had over 20 training places with half of the participants being able to secure full time employment with either ourselves or other employers. Whilst the scheme is of value, we do not receive many applicants from people with additional support needs. It is possible that this opportunity is not promoted amongst young disabled people directly, but it has been a struggle to identify suitable disabled young people to benefit from the funding.

RNIB Scotland have also worked with Shaw Trust and SCVO to secure funding for two of the longer term places specifically for people with long term health or disabilities. These are vital to ensure young people with sight loss are able to gain real and relevant work experience to ensure their future participation in the labour market and we will continue to apply for opportunities as they arise.

In addition to the key stages of children moving into adult services or employment and further education, transitions play a crucial role in the whole life cycle, particularly in the 'third age'. There are a substantial number of older people who experience sensory loss and there is a huge need to prepare people at an earlier point of the life cycle to have their eye health checked and to maintain good sensory care to avoid unnecessary sensory loss in the future.

**Recommendation 25:** The sensory strategy must acknowledge the importance of transitional stages throughout the life cycle and develop

appropriate care pathways to ensure that people experience a seamless provision of service throughout their care journey.

## **24. 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 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. Children and young people who are more vulnerable need support to develop the IT skills necessary for enhanced inclusion in society.

## **25. Training**

The impact of awareness can be staggering. Where staff are aware of sensory impairment, the service can be excellent, but where staff are not, extremely challenging situations can be presented. A serious commitment to invest time in training is essential and whilst training should be delivered in the first instance to front line staff, this needs to be continued on an ongoing basis in partnership with parents, families and carers.

**Recommendation 26:** The sensory strategy should be clear how the mandatory training will be delivered (for example, as part of professional training, online modules, 'champion' model approach) and whether it will be reflected in social care, for example, in Scottish Vocational Qualifications and health or education training as evidenced based practise.

The See Hear strategic framework does not outline who will be responsible for providing the funding for training which is set out in the consultation document.

**Recommendation 27:** The sensory strategy needs to be clear how the cost for the mandatory training will be met, particularly given the current difficulties in sourcing funding for other projects.

It is vital that the sensory strategy highlights how essential it is that access to sensory awareness and more specialist training is targeted at

all levels of the workforce, and particularly in early year's settings. If early year's strategies are to be successful, then there needs to be a clear understanding across the board, so that all support staff know what they should be looking for, why and crucially, what to do about it.

*"There is a lack of awareness from staff all the way through"*

**Service user**

**Recommendation 28:** The sensory strategy must be explicit in how it intends to monitor the training delivery and whether quality standards will be assigned to this. There is a range of training delivered across the eyecare sector and we need to ensure that this standard is not only maintained, but improved.

**Recommendation 29:** There is also a need for the sensory strategy to embed training in sensory awareness across the care standards, so that this training becomes part of mandatory training across all learning disability services, older people's services and dementia specific services.

*"Staff in the eye departments need to be aware of who they are working with – there needs to be training for all levels of staff... Someone calls out your name in the clinic and then walks away... where are you supposed to go? How are you supposed to know where to go? There is no one to show you where your consultant is"* **Service user**

## **26. Conclusion**

RNIB Scotland is in support of the broad aims of the See Hear strategic framework and would like to thank the Scottish Government for the opportunity to respond to this important consultation to meet the needs of people with a sensory impairment.

RNIB Scotland strongly believes, however, that much more work is required to ensure that a sensory strategy is fit for purpose. With an ageing population and the related associated increases of sensory impairment alongside this, it is critical that sensory impairment remains one of the Scottish Government's top priorities.

RNIB Scotland looks forward to seeing how our comments and suggestions have been incorporated into the sensory strategy. We are also keen to play an active role in ensuring that the sensory strategy is successfully implemented across Scotland.

*“The strategy talks about joined up services in Health Board, statutory and third sector – and training/services needs. This doesn’t currently exist at all...well done to this document for suggesting it”* **Service User**

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<sup>i</sup> 'Seeing and hearing it my way'

<sup>ii</sup> Boyce, T., Stone, M K., Johnson, S., & Simkiss, P. (2013). Projecting numbers of falls related to visual impairment. *British Journal of Healthcare Management*, 19(6) 226-229

<sup>iii</sup> Dickey, H., Ikenwilo, D., Norwood, P., Watson, V. & Zangelidis, A. (2012). 'Utilisation of eye-care services: The effect of Scotland's free eye examination policy'. *Health Policy*, vol 108, no. 2-3, pp. 286-293.

<sup>iv</sup> Cameron, J S., Ahmed, S., Curry, P., Forrest, G., & Sanders, R. (2009). Impact of direct electronic optometric referral with ocular imaging to a hospital eye service. *Eye*, 23, 1134–1140

<sup>v</sup> Thurston, M., McLeod, J., & Thurston, A. (2013). Counselling for sight loss: Using systematic case study research to build a client informed practise model. *British Journal of Visual Impairment*, 31(2) 102-122.

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