

6 September 2012

## **Royal National Institute of Blind People (RNIB) Scotland Response to the Consultation on the Integration of Adult Health & Social Care**

RNIB Scotland welcomes the opportunity to respond to this consultation and to support the principle underpinning the integration of adult health and social care. RNIB Scotland recognises that strong and effective partnership must be at the heart of driving better outcomes for the people of Scotland. As the leading charity working with blind and partially sighted people in Scotland and a major partner with a range of integrated eye-care and sensory services we support those with a sensory impairment to live full and independent lives. We believe that the proposals on the integration of health and social care must explicitly recognise the interests and needs of blind and partially sighted people in order to deliver seamless services and better outcomes.

RNIB Scotland research shows that:

- sight loss is set to double by 2031;
- it has a major impact on people's lives;
- this impact is often underestimated;
- the cost of sight loss to society is equivalent to each patient requiring ten hospital admissions a year (RNIB Scotland 2010a).

The future of adult health and social care is critical to those living with sight loss.

RNIB Scotland is committed to working in partnership with others and in particular, to the integration of services where there is a clear focus on

improved outcomes for service users and their carers. In our experience successful integration is often challenging and complex. It is predicated on trust, a clear and simple vision and recognition of the importance of an effective, robust and well-resourced change management programme. Where these factors are not prioritised or fully implemented we have found that integration can be ineffective and costly and ultimately detrimental to service user outcomes. Implementing such a wide-ranging change can be difficult at the best of times and given the current budget pressures and service demands this is even more the case.

RNIB Scotland's mission focuses on the needs of the blind and partially sighted and this response reflects key RNIB Scotland concerns.

## **Blindness and sight loss**

At present, around 36,000 people are formally registered as blind or partially sighted in Scotland, but the true total is estimated to be around 180,000 Scots with sight loss (RNIB Scotland 2010a).

It is also estimated that there are 1,000 to 2,000 young people in Scotland with sight loss, and people with learning disabilities are especially vulnerable: of the 120,000 people in Scotland who have a learning disability, at least 30 per cent will have significant undetected sight loss. RNIB research shows that people with learning disabilities are 10 times more likely to have serious sight problems than other people (RNIB 2010).

There were 247,278 people diagnosed with diabetes in Scotland at the start of 2011 (NHS Scotland 2012) and diabetic retinopathy is now the leading cause of blindness among the working-age population. Someone with diabetes has a 10 to 20 times greater chance of being registered blind.

By 2030, the number of people with sight loss (without intervention beyond the current provision) is expected to double from around 180,000 to almost 400,000. This increase is mainly due to a large rise in the elderly population but a variety of health factors, such as Scotland's persistently poor health record, also play a part.

The expected increase in the number of people with sight loss will mean a corresponding increase in demand for services to prevent and treat sight problems as well as for services to support those with sensory loss to live independently.

The annual cost of sight loss per person is around £17,646 - roughly equivalent to ten hospital admissions per year. In total, the NHS and the public sector in Scotland spend a minimum of £194 million annually on sight loss conditions. The broader budget implications for the economy and to society are estimated at a further £434 million. It should be noted that this figure does not include the new wet Age-Related Macular Degeneration (AMD) treatments. Total costs are projected to rise by around £120 million a year (RNIB Scotland 2010a).

Early diagnosis and treatment can prevent up to 98 per cent of severe sight loss. RNIB Scotland wishes to highlight the following key principles of improvement, prevention and inclusion.

### **Moving Forward - Future areas for improvement**

The Scottish Vision Strategy (SVS) was established by a wide alliance of statutory health and social care bodies, voluntary organisations, eye health professionals, government representatives and service users to make a lasting difference to the eye health of Scottish people and to improve the lives of those who have lost sight.

For people living with sight loss, the SVS seeks to ensure speedy referrals, person-centred care pathways and more rational and cost effective methods of operating.

To achieve this, an Implementation Plan was drawn up in 2008 with clear objectives and outcomes. The plan had three strategic 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 (RNIB Scotland, Eyecare Scotland and Optometry Scotland 2008).

The Scottish Government has made significant investment in eye-care services across Scotland since 2006. Whilst this has enabled important developments to take place the SVS Advisory Group has identified further areas where improvement can be made (RNIB Scotland, Eyecare Scotland and Optometry Scotland 2012).

Integration of adult health and social care must make an explicit commitment to improve eye health care, prevent avoidable sight loss and promote the inclusion of blind and partially sighted people.

The Scottish Government's proposals should include the provision of one-year post-diagnosis support for all people newly registered blind or partially sighted to echo the recent commitment to provide such support for people with a diagnosis of dementia. This level of support would address all three strategic objectives - improvement, prevention and inclusion – outlined in the Implementation Plan of the Scottish Vision Strategy.

## **Improvement: Improving the eye health of people of Scotland**

Early detection of sight-threatening eye conditions is crucial to prevent unnecessary sight loss. Early detection and prevention preserves functional vision for longer, avoiding falls and further costly complications and treatment.

- Anticipatory care - Require Health Service personnel and Social Work assessors to develop anticipatory responses to the management of eye health within assessment services, particularly for high risk groups such as learning disability, stroke, dementia and diabetes.
- An estimated 579,000 adults with learning disabilities in the UK have refractive error and an estimated 53,300 adults with learning disabilities have severe refractive error (Emerson & Robertson 2010). A formal vision assessment should be undertaken as part of all health and social care assessments of people with a learning disability in Scotland. Young people with a learning disability should have a formal vision assessment on leaving school to ensure that undetected sight loss does not adversely impact on their transition (RNIB Scotland 2011).
- Formal vision assessments should also be built into all health and social assessments for other high risk groups including those living with dementia or stroke.
- There is considerable evidence that the take-up of adult health and social services by Minority Ethnic groups lags behind other population groupings. RNIB Scotland has developed a number of innovative approaches to counter-act this effect. Integration of adult health and social care should take this factor into account.
- Eye Health Checks - Continue to advertise and promote Eye Health Checks to everyone in Scotland to ensure that sight-threatening conditions are identified earlier when treatment can arrest or reverse damage.
- The development of systematic and routine monitoring of eye health care and the best use of IT in relation to electronic patient records (EPR) should be further explored. Self management and regular eye sight checks are vital but it is also necessary to maximise the implementation of public health

strategies in relation to eye-care. The roll-out of the new electronic referral system provides an unprecedented opportunity to improve Scotland's eye health and social care services for future generations.

- 
- **Prevention: Eliminating avoidable sight loss and delivering excellent support to those with a visual impairment**
  - To include improved coordination, integration, reach and effectiveness of Eye Health Services (EHS) and support by:
    - The implementation of the new integrated electronic referral system between optometrists and EHS.
    - AMD Services – the commissioning of a five year forward plan for the provision of services concerning macular related diseases such as AMD, the leading cause of sight loss among older people.
    - Resource and implement the Scottish Sensory Impairment Strategy to be published during 2012/13.
    - Promote Self-Directed Support especially ensuring that Local Authorities build effective assessment processes which take full account of the impact of sight loss, known and unknown, on an individual's wider health and well being, and that Direct Payments truly reflect the person's care needs.
    - Workforce - improvements to workforce training to include awareness raising of eye conditions and the impact of sight loss.
    - Emotional Support – especially ensuring that no one newly diagnosed with sight loss is left without access to emotional support through a lack of Vision Support Service.
    - Falls services – the routine inclusion of eye health checks within Falls Strategies and practice guidelines.
    - 'Hidden' sight loss – ensuring a functional vision assessment for those with a Learning Disability or suffering from Dementia.
    - Functional vision research – notably in the field of stroke and sight loss.
    - Rehabilitation - assess the current provision of rehabilitation services for adults and habilitation services for children and young people.
-

- **Inclusion: Enhancing the inclusion, participation and independence of blind and partially sighted people**

- The goal is to improve the attitudes and actions of service providers in terms of education and employment. For example, reducing the unemployment rate for blind and partially sighted people in Scotland should be prioritised within employment. Both health and social care organisations can currently promote independence through supported employment initiatives. Unfortunately to date there has been relatively low engagement in this area. Within any new structures the opportunity to support the employment of disabled people through Article 19 should be supported. Article 19 enables public bodies to help support disabled and blind and partially sighted people. (See RNIB Scotland 2010b).

- Removing barriers to inclusion is critical for all disabled people to achieve their potential. For the visually impaired these barriers include the built environment, the needs of specific population groups (for example older people, people with learning disabilities, people with stroke related sensory loss, etc), welfare planning and access to communication tools. Action is needed to:

- Continue to address the existing barriers in the built environment, to transport and in the ever developing technological infrastructure which restrict the opportunities available to blind and partially sighted people.

- Promote accessible transport and associated infrastructure.

- Ensure that the specific information needs of minority ethnic groups are addressed in relation to eye care and sight loss issues.

- Ensure that expert advice and support is available so that people with sight loss, and other disabilities, are able to maximise the income they are entitled to so they can live with independence and dignity.

- Ensure accessible reading materials so that blind and partially sighted people are not marginalised.

- Enable blind and partially sighted people to acquire the awareness, skills and knowledge necessary for full digital access.

- Encourage public bodies to ensure that their online presences, in the shape of websites, are accessible to blind and partially sighted people.

- 

- **Conclusion**

Whilst we support in principle the integration of adult health and social care and recognise the potential benefits for our services we would like to highlight the following:

- Integration of adult health and social care must make an explicit commitment to improve eye health care, prevent avoidable sight loss and promote the inclusion of blind and partially sighted people and support their families and carers.
- RNIB Scotland believes that integration of health and social care must include the interests and needs of blind and partially sighted people in order to deliver seamless services and better outcomes.
- It is essential that these outcomes are identified as an integral part of the integration agenda to ensure the availability of resources which will sustain high quality support and care for blind and partially sighted people.
- Evidence has shown how participation can improve service quality (Scottish Health Council, 2011). RNIB Scotland wishes to see a strong role for third sector organisations and especially the voices of services users, carers and public representatives in shaping the development and delivery of integrated services.
- Whilst new technology offers many opportunities to blind and partially sighted people it is also important to ensure them equal access and this should be reflected in the integration of adult health and social care.
- It is accepted that risk will always be an element of risk in any change management programmes. Although sensory loss is a relatively low incidence grouping it impacts upon many other areas including learning disability, dementia, stroke and autism. RNIB Scotland believes it is crucial not to lose sight of sight loss.

## References

Emerson & Robertson 2011. The Estimated Prevalence of Visual Impairment among People with Learning Disabilities in the UK. (Improving Health and Lives: learning disabilities observatory).

NHS Scotland 2012. Scottish Diabetes Survey 2011. Scottish Diabetes Survey Monitoring Group.

RNIB Scotland, Eyecare Scotland and Optometry Scotland 2008. Scottish Vision Strategy. RNIB Scotland.

RNIB 2010. Research Briefing: Estimates of the number of adults in the UK with learning disabilities and visual impairment.

RNIB Scotland 2010 a. The cost of sight loss Scotland: 2010-2020.

RNIB Scotland 2010b. Article 19: Making it work for people with sight loss.

RNIB Scotland 2011. Don't Lose Sight of Sight Loss: Manifesto for the 2011-2015 Scottish Parliament.

RNIB Scotland, Eyecare Scotland and Optometry Scotland 2012. Scottish Vision Strategy: Success in Sight? Interim Review 2012.

Scottish Health Council 2011. Improving quality through participation.