About the ALLIANCE

The ALLIANCE's vision is for a Scotland where people of all ages who are disabled or living with long term conditions, and unpaid carers, have a strong voice and enjoy their right to live well, as equal and active citizens, free from discrimination, with support and services that put them at the centre.

The ALLIANCE has three core aims; we seek to:

- Ensure people are at the centre, that their voices, expertise and rights drive policy and sit at the heart of design, delivery and improvement of support and services.

- Support transformational change, towards approaches that work with individual and community assets, helping people to stay well, supporting human rights, self management, co-production and independent living.

- Champion and support the third sector as a vital strategic and delivery partner and foster better cross-sector understanding and partnership.

Introduction

The ALLIANCE welcomes the introduction of the See Hear sensory impairment framework and acknowledges the importance of this agenda, particularly in light of demographic changes and Scotland’s ageing population. In Scotland, approximately 850,000 people have a hearing loss, 180,000 have sight loss and 5,000 people have a dual sensory impairment¹.

A number of the ALLIANCE’s members work with people who have a sensory impairment. On 5 June 2013, the ALLIANCE organised a roundtable session on the

See Hear strategic framework and invited contributions from the Scottish Government, COSLA, RNIB Scotland, Action on Hearing Loss Scotland, Alzheimer Scotland, Deafblind Scotland, Hearing Link Scotland, Diabetes UK, Sense Scotland, Visibility and Deaf Connections. The views gathered at this meeting have been used to influence the ALLIANCE’s consultation response.

As this strategy intends to run for the next decade, the ALLIANCE recognises the need to break this down into priorities across different timescales (Appendix 1, Page 18). However, it remains unclear as to who will be both measuring and monitoring the impact of these priorities. The ALLIANCE would welcome the introduction of a “gatekeeper review” at different junctures during the strategy’s lifetime and would also encourage the Scottish Government to give consideration to the creation of demonstrator areas, as have been adopted in the dementia strategy, as a way of showcasing the impact of the strategic framework.

Consultation Questions

Care Pathway

The strategy identifies key factors that need to be in place to ensure the pathway is successful (Page 11 para 6.7). Which of the key factors are most important for a successful pathway?

- A commitment from statutory agencies to seek to agree the maximum possible consistency of approach across Scotland, and ensure similar access to services across Scotland.

The ALLIANCE acknowledges that this will require a strong approach from across statutory agencies to ensure that such a commitment is achieved. For this to be successful will require an approach which takes this forward as part of, and alongside, other national strategies related to the provision of services from statutory agencies.

- A commitment to awareness raising training for front line staff who may have to deal with people with sensory impairments.

Improving the understanding of sensory impairment across the health and social care workforce is an important part of ensuring that they work in a person-centred way that focuses on their needs and requirements. Whilst many older people experience some level of sensory impairment, many ALLIANCE members have expressed concern about the level of awareness of sensory impairments in care homes for older people. NHS Education for Scotland has produced a sensory impairment awareness training
manual\(^2\) which provides a good model for further awareness training across the country.

However, the ALLIANCE believes that this should not be completed in isolation and would call on the Scottish Government to introduce an overarching training programme that focuses on the importance of adopting a human rights based approach to the provision of health and social care.

**Do you think that any key factors have been missed?**

The ALLIANCE would encourage the Scottish Government to consider the development of strategies to reduce waiting times for access to sensory specialists. Our members have expressed particular concern about the waiting times for access to rehabilitation.

**Areas for action**

The strategy identifies areas for action that should be addressed going forward (Page 13-16)

**Recommendation 1 – Audit of spend**

As the number of people who have a sensory impairment grows, we need to increase our understanding of how spending on sensory impairment is spread across the public sector. Despite being community and primary care services, a lot of sensory impairment services sit within the acute sector. This causes problems in terms of access and budget arrangements.

The level of spending on sensory impairment is considered to be low, despite the demand for services being high and often unmet. For instance, the annual cost of sight loss to the NHS per person is around £17,600. This is roughly equivalent to ten hospital admissions\(^3\). At the same time 54% of deaf and hard of hearing people had never had an assessment carried out by social work services; with nearly 40% saying they did not have an assessment because they were not aware the services existed\(^4\). Gaps in provision and unmet need can result in a higher risk of people developing other conditions, for instance mental health issues.

\(^2\)http://www.knowledge.scot.nhs.uk/media/CLT/ResourceUploads/4000422/Basic%20SI%20Awareness%20resource.pdf  
\(^4\)http://www.actiononhearingloss.org.uk/~/media/Documents/Scotland/Policy%20Research/AOHLScot_LG_elections_2012.ashx
The ALLIANCE believes that an audit of spend should seek to establish the level of unmet need, consider current levels of service provision and that required to meet the predicted future need. The Scottish Government should also set a clear date by which the audit will be complete and recommendations for future actions in place.

Recommendation 2 – Basic sensory screening

The diagnosis of a sensory impairment can be a problem area. Action on Hearing Loss Scotland encourages people to have a hearing check as this is a relatively non-evasive intervention. There are, however, significant concerns about the current capacity of audiology to meet the demand.

Different information gathering systems are used by the NHS centrally, GPs and social work departments. These systems need to be better jointed in order to be of greater benefit to the anticipatory and preventative agendas.

The national newborn hearing screening programme which picks up potential hearing loss, however this information is not shared elsewhere. This information should be shared, for example with local education authorities to influence decisions about future priorities. There needs to be a much more joined up approach here.

Recommendation 3 – Sensory awareness training

Improving the understanding of sensory impairment across the health and social care workforce is an important part of ensuring that they work in a person-centred way that focuses on their needs and requirements. Whilst many older people experience some level of sensory impairment, many ALLIANCE members have expressed concern about the level of awareness of sensory impairments in care homes for older people. The ALLIANCE believes that the Scottish Government should consider how training packages that are already available can be used to maximum effect, for instance NHS Education for Scotland has produced a sensory impairment awareness training manual\(^5\) which provides a good model for further awareness training across the country.

Sensory impairment figures highly in both the National Falls Strategy and the National Dementia Strategy. We must learn from the example of the dementia champions, who are one of the “change agents” within the dementia strategy. Their role includes 6 months’ worth of assignments and follow through with consultants, dementia assignments etc. This ensures that they do not go back as lone voices.

\(^5\)http://www.knowledge.scot.nhs.uk/media/CLT/ResourceUploads/4000422/Basic%20SI%20Awareness%20resource.pdf
The ALLIANCE believes that this should not be completed in isolation and would call on the Scottish Government to introduce an overarching training programme that focuses on the importance of adopting a human rights based approach to the provision of health and social care. Such training should be available as part of undergraduate programmes to increase understanding of long term conditions and improve practice.

Some ALLIANCE members have also expressed concern about a lack of a trained, qualified people in the healthcare workforce to work with people who have a sensory impairment. Particular concerns have been highlighted about the number of optomologists, rehabilitation specialists and interpreters.

Recommendation 4 – Local partnership work

There is evidence that some GPs/clinicians are not aware of the specific pathways related to sensory impairment. ALLIANCE members have expressed concern that some people with sensory loss can wait up to 10 years for diagnosis and are not moved on with referral and onto the appropriate pathways. There is often a lack of understanding from frontline staff, including GPs about the implications this has for the individual.

Whilst care pathways and Managed Clinical Networks are often well developed, the evaluation of their impact is often unclear. We would encourage the Scottish Government to consider how it can assess the value of the care pathway and its effectiveness after its implementation.

GPs are one of the biggest gatekeepers to achieving a preventative approach. In order to get their buy in, however, there has to be something within the GP contract to provide an incentive. The strategic framework should contain some reference to a link to that contract.

Recommendation 5 – Local information

ALLIANCE members have expressed some concern about a lack of access to communication support and sometimes this is re-enforced by a lack of awareness of existing information. Often this is because staff themselves do not know about information and strategies that can assist people. The Scottish Government must consider how it can further promote and mainstream the provision of such information.

A lot of people with sensory impairment are not getting the adequate support they need to stay in work. In particular, there is work to be done with employers around access to equipment and training of staff to improve understanding of the continuing role people with a sensory impairment can play in the workplace.
Recommendation 6 – Equality Act 2010

ALLIANCE members have highlighted that many IT systems can be prohibitive to people with sensory impairments, even in public buildings such as libraries. Despite an existing legal framework to prevent this, access remains a great issue due to security systems and updates. This can be simple things that cause significant problems for people – for instance preference to Word files over "PDF" files.

The onus is on the individual to take forward a challenge under the Equality Act, this can be a barrier for people with sensory impairment and as a result no one is enforcing the Act.

**Are there any other areas for action that you would like to see included within the strategy?**

The ALLIANCE believes that the following areas of action require a greater emphasis within the strategy:

- People should have access to reliable information about their rights to different services. Founding the dementia strategy on a charter of rights has been a key success of the dementia strategy. This comes in the context of the development of Scotland’s first National Action Plan for Human Rights (SNAP) by the Scottish Human Rights Commission. SNAP recommendations are likely to look at people being able to understand and have the confidence to express their rights, as well as using a rights based approaches within the health and social care workforce. The Scottish Government should consider how such an approach can underpin the strategic framework for sensory impairment.

- Addressing the low awareness of services/entitlements and low prioritisation of sensory health amongst ethnic minority groups.

- Improving children’s services, particularly in reference to improving access to technology in schools, individual independence and a lack of a qualified workforce to assist with mobility training for children

**Current provision of services**

**Please comment on the current provision of sensory impairment services as either a service provider or service user. If you have any experience of sensory impairment services, please let us know what you think of them: this should include any experience of one-stop shops.**
Whilst it is early in their development, the ALLIANCE welcomes the introduction of the one-stop shop approach to service delivery as a shift away from traditional models towards the local delivery of additional support, advice and information provided within the same location.

Anecdotal evidence from ALLIANCE members suggests that the introduction of the one stop shops has had a positive impact so far. Encouraging closer joint work has been a positive move, but we would encourage the Scottish Government to undertake a full evaluation of the one stop shop approach to assess the value this has had for people who have a sensory impairment and establish any potential improvements.

**Children's services**

*Does this strategy properly reflect the current climate and developments in policy and practice for children and young people particularly in relation to the Getting it Right for Every Child approach and the Doran Review?*

We are concerned that an adequate weight has not been placed on issues relating to children and young people who have a sensory impairment and further consideration of these issues is required.

The strategy is published in the context of developments related to children such as the Children and Young People’s Bill and the Doran Review 2012. As part of the health and social care integration process there is now a requirement to undertake joint strategic commissioning in each partnership area. As the Doran Review addresses specialist commissioning, this issue crosses over between this strategy and the health and social care integration agenda.

**For more information**

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