



See Hear

A strategic framework for meeting the needs of people with a sensory impairment in Scotland

Health and Community Care: Integrated Adult Care and Support Division

28th June 2013

Available in other formats on request.

Sense Scotland, 43 Middlesex Street, Glasgow G41 1EE

Tel: +44 (0) 141 429 0294 Fax: +44 (0) 141 429 0295 Text: +44 (0) 141 418 7170

www.sensescotland.org.uk info@sensescotland.org.uk

Registered as a company limited by guarantee in Scotland 147570 Registered Scottish Charity Number SC022097

1. Introduction

- 1.1. Sense Scotland is a leader in the field of complex communication support needs and promotes the use of innovative services for people who are often marginalised when traditional models of support are used. We offer a range of services for children, young people and adults whose communication support needs result from a range of impairments including deafblindness; sensory impairment; physical or learning disabilities. Our services are designed to provide continuity across age groups and we work closely with families and with colleagues from health, education, social work and housing.
- 1.2. As a major provider of services in this area for over 25 years Sense Scotland are concerned at the process involved in producing the consultation document. It is unclear how the strategy group was initially selected - only after several approaches were Sense Scotland invited to attend a meeting. Thereafter meetings were postponed or cancelled with short notice, and finally reconvened minus a number of members. We were not notified of either the change in membership of the meetings, or the reasons behind it. We are concerned that this implies a marginalisation of the people Sense Scotland work with. We have made representation on this point on a number of occasions in the past.
- 1.3. Following feedback from staff who attended consultation events we are aware that it would have been useful to have had an understanding of the results of funding that had gone to pilot projects. External evaluation of projects and results would have led to informed decision making on the strategic framework. For example, external evaluation would have provided a transparent account of good practice that could then be shared with other providers. Instead there is concern that a compilation of good practice examples could be drawn mainly from a single organisation. A representative and transparent mechanism of accountability would have given confidence in proposed elements of the strategy.
- 1.4. We are not convinced that the consultation report's recommendation, to identify all direct and indirect spend on sensory impairment services with a view to pooling that spend and redistributing it, is helpful. Without an evidence base, externally evaluated, of what works it is difficult to see what would be gained from this approach. (As we note below a strong evidence base on direct / indirect spend in the sensory impairment fields does exist, having been carried out by a reputable company that reported on measured outcomes across a range of variables.)
- 1.5. We are concerned that the consultation questions are framed from the assumption that the proposed framework is the correct one, rather than inviting comment on whether it will meet the needs of people within the full range of sensory impairment. More fundamentally than this, a framework is not the same as a strategy, and can not meet needs without being part of a strategy.
- 1.6. We understand that the Sensory Impairment Strategy Group's remit was to produce minimum standards of service. The consultation document does not do this but instead sets out a general overview. Existing standards that have been developed, and are used, by others appear to have been set aside. It

would have been helpful had evidence gained from previous relevant exercises been referred to

- 1.6.1. In education for example Shetland has for many years had a strategy and continues to evolve that strategy. RNIB Scotland themselves produced minimum standards relating to education of visually impaired and blind children; although now relatively old they are still operationally relevant and in use.
- 1.6.2. In the care sector minimum standards for Deaf and hard of hearing people were produced in consultation with a wide group of stakeholders. The Scottish Best Practice Standards. Social Work Services for Deaf, deafened, hard of hearing and deafblind people, October 2001, Multi-agency Taskforce document set out minimum standards based on widely accepted and implemented principles of Choice, Dignity, Information, Participation, Diversity, Safety and Equality. In contrast, See Hear demotes principles of intervention support to a minor role.
- 1.6.3. Talking SENSE in the Highlands (Highland multi-agency report on an integrated strategy).
- 1.6.4. Shetland Isles Council strategic developments which have evolved with circumstances and population change – a prerequisite for a small island population.
- 1.6.5. A Joint Strategy for People with Physical Disabilities and Sensory Impairment (Renfrewshire).
- 1.7. While it can be argued that these documents reflect current rather than future periods (e.g. 2009-14 strategy document), they do take a strategic framework approach, identify existing partner agencies and reflect practice that has been discussed, agreed and evolved over several years. The consultation document appears not to take account of these factors and instead offers a model that is driven from the top down.
- 1.8. We identify these documents as examples, in order to highlight the fact that much work has taken place involving multi-agency partnerships, work that evolved to take account of local circumstances. It appears to have been largely discounted.

2. Comments on Consultation Questions

1. The strategy outlines a care pathway (page 10).

(a) If you are a service user and/or carer, please tell us what difference you believe the implementation of the pathway will make to the services you experience.

The report refers throughout to 'care pathways'. These terms reflect a medical model of support and provision for people with a sensory impairment and, if they are to appear in a strategy, should operate within a higher level framework based on principles. It would be helpful if this were made clearer.

(b) How can we best ensure that services and support meet your needs?

We have responded elsewhere as a provider of services.

(c) If you are a care provider, what changes will you need to make to implement the pathway?

Clinical / care / critical pathways or care paths or integrated care management plans are used worldwide. Their impact remains unclear in many areas, and this may in part be due to having over 80 different definitions (PubMed search 2000-3 articles). As a result and following international discussions the European Pathway Association – a leader in the field of care pathways – agreed the following definition: *a complex intervention for the mutual decision making and organisation of care processes for a well-defined group of patients during a well-defined period. With the following characteristics:*

- (i) An explicit statement of the goals and key elements of care based on evidence, best practice, and patients' expectations and their characteristics;*
- (ii) the facilitation of the communication among the team members and with patients and families;*
- (iii) the coordination of the care process by coordinating the roles and sequencing the activities of the multidisciplinary care team, patients and their relatives;*
- (iv) the documentation, monitoring, and evaluation of variances and outcomes; and*
- (v) the identification of the appropriate resources.*

One of the main, if not the main target groups to address therefore would be the biggest group of expected beneficiaries i.e. people in older age groups. Older age groups are expected to be associated with the biggest increase in sensory impairment, with the report citing an expected doubling within a few years. Therefore successful intervention could aim to target this group for impact in this particular age group with lessons learned applying across to others with sensory impairment. An important question then is: how would a care pathway, or pathways, in sensory impairment address the needs of this group, and what improved outcomes would be expected? The strategy document does not address this in sufficient detail.

Applying the E-PA definition to older age groups presents difficulties because this group is not well-defined but characterised by frequent and multiple pathologies: with number and frequency of pathologies increasing alongside increased sensory impairment.

The requirement for an explicit statement of goals and key elements of care based on evidence, best practice etc. (see E-PA definition of care pathway) is also difficult to meet, because individual circumstances are highly variable. This is again because the impact of sensory impairment will have radically different effects depending on highly individualised circumstances. In part, this is determined by whether, as is likely, that person is also part of a second, third and possibly fourth care pathway. The variability of individual circumstances is compounded by multiple pathologies accompanying increasing age; it is also compounded by geographical and proximity factors. The strategy should set out how it will address these compounding factors.

2. The strategy identifies key factors that need to be in place to ensure the pathway is successful (Page 11 para 6.7).

- (a) Which of the key factors are most important for a successful pathway?
- (b) Which are the most challenging to put in place?
- (c) Do you think that any key factors have been missed?

See our comments on care pathways above.

3. Areas for Action

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

- (a) Which of the areas for action will be the most challenging to implement?
- (b) Which of the areas for action will make the biggest difference and why?
- (c) Are there any other areas for action that you would like to see included within the strategy?

4. Comments on Recommendation 1:

- 4.1. The action recommends undertaking an audit of all current spend on sensory impairment, including spend that relates to carers, across statutory Health and Social Care and third sector agencies in relation to specialist provision and to those elements of other service provision that impact on people with a sensory impairment. It would be helpful to understand the thinking behind this, particularly given the issues noted earlier about multiple pathologies, and varying circumstances and support needs.
- 4.2. We are not convinced that the recommended audit would add evidence based information that would add value to existing information. One of the best worked examples in this area is the Deloitte report **The economic impact of vision impairment and blindness in the Republic of Ireland¹**. While this report clearly cannot be used directly to estimate costs and economic options for Scotland, the fact that populations sizes are similar, predicted demographic change is similar, service delivery outcomes and frameworks are similar, would suggest that its findings would have been of interest.

¹ The economic impact of vision impairment and blindness in the Republic of Ireland. (2011) NCBI (National Council for the Blind of Ireland).

5. Comments on Recommendation 2:

- 5.1. *Local partnerships should consider options for the introduction of basic sensory screening, for example, for people of a certain age, and at agreed times in their care pathway.*
- 5.2. It is essential that recommendations are arrived at only after synthesising available evidence. For example, in the case of childhood screening, the views of the National Screening Committee, the Royal College of Ophthalmologists, the British and Irish Orthoptic Society, the Health for All Children report and others, were that, apart from screening between the years of 4 and 5, no other screening should be offered and that vision screening in 7 year olds (and by implications older children) should be discontinued. See Hear appears to imply that this should be revisited. It would have been helpful to have had evidence to say why this was important.
- 5.3. The findings of the above authoritative bodies were reinforced in a 2010 follow up survey undertaken by IPSOS and University of Edinburgh on behalf of Scottish Government Social Research². This report identified the important finding that, although then extant age-based screening was not particularly useful, problems that did arise were to do with **follow-up and treatment**. A strategy report that is evidence based should address these and other findings.

6. Comments on Recommendation 3:

- 6.1. *There should be mandatory training in sensory awareness and assessing for non-complex needs across staff in health and social care settings, targeted in the first instance on older people's services.*
- 6.2. We support this recommendation in part, and only if it is re-worded. In its current form it is ambiguous. We think it is intended to mean:
"Staff in health and social care settings who work with people with non-complex support needs should receive [mandatory] training in sensory awareness. In the first instance this should be targeted on older people's services."
- We do not agree that staff in this setting should receive training in assessment. Instead, evidence based questions appropriate to their particular care role should be identified and introduced. These should reflect the reality of for example delivery of home care by staff working within minimal time and task constraints to provide care packages.

The explanatory information (See Hear para. 7.7) cites home carers as a recipient group of training. Scottish Government will want to consider carefully the impact of requiring *mandatory* training in sensory impairment, within the context of any single outcomes agreement through CoSLA. We

² Lorraine Murray, John Ravenscroft & Jennifer Skillen (2010) School-age sight testing in Scotland Research. Scottish Government Social Research (Health and community Care).
<http://www.scotland.gov.uk/Resource/Doc/317220/0101040.pdf>

would welcome such a commitment, but both training and recompense of a more skilled workforce will need to be fully funded.

7. Comments on Recommendation 4:

7.1. *Relates to care pathways.*

7.2. See our earlier comments on care pathways.

8. Comments on Recommendation 5:

8.1. *There should be robust systems for maintaining information locally, and sharing this between agencies, in relation to people who have received a diagnosis of a sensory impairment at any time from birth onwards.*

8.2. See our earlier comments on care pathways.

8.3. The issue of data collection on sensory impairment appears at first to be relatively straightforward. However a number of factors need to be taken into account. An important question for public health is whether in fact the reporting of visual impairment is the best measure of the likely costs and benefits to be accrued from health and care measures. Nor does the strategy document set out a framework within which data collection could be harnessed.

8.4. Official statistics may under-report prevalence figures. There is good evidence from sub-Latino epidemiological studies that a more useful health indicator is self-reported visual functioning. For example:

8.4.1. Compared to people with no visual impairment, those with bilateral mild and unilateral or bilateral moderate/severe visual impairment report greater difficulties in performing most vision-dependent daily activities. They also report poorer vision-related mental health. Because most visual function subscale scores are significantly lower in people with bilateral mild and/or unilateral/bilateral moderate/severe visual impairment, health care providers should consider intervention with these people. (This would have a direct impact on older people because of accumulated multiple pathologies – doing small things can result in big improvements in daily living, wellbeing etc.).

8.4.2. There is an inverse correlation between self-reported depression and low visual function scores. This is important for several reasons but one to draw attention to is that visual function scores can be low but visual acuity remain normal or near normal (with corrective lenses/spectacles). The implication is that there is a pool of functional pathology that affects people's ability to access everyday life. Identify how to remedy this and you have better wellbeing. This kind of evidence has major implications for delivery of improvement outcomes but does not feature in the care pathways mentioned in the report.

8.4.3. Self-reported visual function scales are better indicators of health and illness than those such as Short Form Health Outcome measures, General Household Surveys etc.

8.4.4. It would be helpful to balance consideration of clinical manifestations with due consideration given to self-reported visual functioning.

9. Comments on Recommendation 6:

9.1. *Compliance with the Equality Act 2010 should be scrutinised in relation to sensory impairment, particularly in relation to communication, and consideration given as to what future action may be required.*

9.2. We should assume compliance with the Equality Act 2010 and associated policy. The strategy should be the document that outlines what particular future actions may be required to intervene in areas which are non-compliant, based on evidence of what works. The wording of this question implies a delay in forming the Strategy itself.

9.3. *Our response has included references to existing relevant reports and recommendations that could inform the strategy. Similarly, in relation to Equality Act compliance significant developments have taken place on making Scotland a more inclusive nation e.g. Principles of Inclusive Communication - An information and self-assessment tool for public authorities, Scottish Government 2011.*

4. 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.

Sense Scotland is a provider of services, as described in paragraph 1. The daily experience of the people we support with sensory impairments underlines the need to consider all aspects of their lives within any strategy – health (usually complex); education; travel; employment and family life are just some of the areas.

We would be happy to discuss any aspect of this work in more detail.

5. What difference will the implementation of the strategy make to your life?

6. 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?

The consultation helpfully sets out the intention to consider the impact of sensory impairment on children and young people. However, given the wide-ranging nature of support needs in this age group and the report's understandable emphasis on the

needs of older people with sensory loss, the impact of that framework on children and young people will require further clarification. An important issue is how the framework will help to ensure consistency with Girfec – will sensory impairment sit outwith a Girfec approach, or be embedded within, and how might this be achieved in practice. The strategy should identify how specialist professionals will work within a broader inter-agency approach. A useful example here, although not referenced, is Donaldson's School publication 'A template for success – positive transitions into further education, training and work for deaf young people in Scotland'. The relationship of the Lead Professional and Named Person might also be discussed in more detail in this section.

It is perhaps too early to say how the strategy document will relate to the Doran Review. This is to be expected as the first meeting of the Strategic Commissioning Implementation Board met after publication of the consultation.

7. Do you have anything you wish to add to the Sensory Impairment Strategy or any other general comments that have not been covered by the questions?

For more information on these issues, please contact:

Dr. Stuart Aitken **saitken@sensescotland.org.uk**
Senior consultant
Sense Scotland
43, Middlesex Street
Kinning Park
Glasgow
G41 1EE