



Scottish Sensory Impairment Strategy Consultation – A Response

BACKGROUND.

Deaf Action is the largest deaf-led registered charity working across Scotland, with services in Edinburgh and the Lothians, Fife, Tayside, Highland, and in Aberdeenshire. Established in 1835, we have worked together with deaf people to raise awareness of the needs and rights of those with sensory needs, to challenge discrimination, and provide services to promote independence and quality of life.

The following comments in response to the questions posed in the Scottish Government's 'See Hear' Strategic Framework Consultation paper are based on our experience as a service provider, and on a series of consultation meetings held with service users, as well as individuals who did not use services, some of which were carried out in conjunction with our partners in East Lothian, Midlothian, West Lothian and the City of Edinburgh Councils.

INTRODUCTORY REMARKS

Whilst acknowledging the very positive development of a proposed strategic framework for meeting the needs of people with a sight loss and who are deaf*, and the valuable information on definitions, prevalence, policies and practice expectations, we did not find the document easy to comprehend. Questions posed did not appear to relate directly to recommendations for action. We were disappointed that the document was released in print form prior to other formats being available, and in particular that there was not a BSL translated link on the Scottish Government website. Whilst a BSL DVD version was later produced, information on how this might be obtained was not readily available. An 'Easy Read' version of the Consultation document was only inadvertently seen, and again, information about this was also not widely circulated. For BSL users, the title 'See Hear' was misleading as they were most familiar with 'See Hear' as the title of a BBC series for deaf people, and were confused, thinking the document was in some way associated with the programme.

. Some disappointment was also expressed by those who attended public meetings arranged by the Scottish Government that the practical arrangements (layout of room, acoustics, knowledge of how to use communication

support/interpreters) were not ideal, and there seemed to be limited knowledge of how to communicate directly when deaf people were addressed.

RESPONSE TO QUESTIONS POSED:

The comments below summarise the views of Deaf Action and deaf people consulted.

1. a. Care pathways 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

A number of people with sensory needs did not understand what a 'care pathway' might mean, although those we met with were agreed that it was important that people knew where to go for support and were quickly signposted to the range of services which might be available. We were frequently told that whilst people had been issued with hearing aids, it was often years afterwards, and *'just by luck'* that they found out that there were other support services available, such as specialist equipment (flashing doorbells/TV loop systems/ fire alarms) and lipreading classes.

One individual told of a lack of support after having had a cochlear implant operation *'I locked myself into my room for 3 days and regretted what I had done'* A general consensus view was that for people who were hard of hearing, things had to *'be desperate'* before they were offered appropriate support, although adult BSL (British Sign Language) users who attended the consultation meetings overall felt that they had good Deaf community links/networks to know what might be available to support them. Concern was expressed for younger deaf children who might not have access to Deaf community networks upon leaving school.

A number of people stated that they had not been aware that their hearing was deteriorating although they subsequently realised that it was this which was causing deterioration in social relations within their families, communities and at work

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

Everyone who participated in the consultation exercise felt that there should be some kind of registration process for people diagnosed with a hearing loss, which would enable information and follow up support to be offered. There was a general willingness for information to be shared across sectors, believing that better statistical information should lead to improved services, with the proviso that individuals should be aware of just what information was being passed on – and that they would have a right of veto.

BSL users were afraid that their need to communicate in their language would be overlooked or ignored. Ideally, those providing services should themselves have BSL skills, but it was recognised this was not always possible. We were often told of examples where either no professionally qualified interpreter was provided, or where the Deaf person themselves had to take on the responsibility of making sure that an interpreter would be available. Sometimes service providers would insist that the Deaf person bring a family member along, or try to lip-read them, or to communicate by writing. Deaf people were embarrassed (many Deaf people have poor levels of literacy as English is not a primary language) and felt belittled by this approach.

Deaf BSL users also gave examples of poor levels of support being available to those who needed residential/nursing home care, where no staff were able to use sign language, and the likelihood of increased mental health issues being experienced. There was particular concern for those who had dementia. The suggestion was made that a small specialist unit should be established as part of a larger service, where more relevant support could be provided. Those who were hard of hearing gave us examples of care staff or nursing staff unable to help someone change a battery in their hearing aid, or help someone put their hearing aid in, leaving them on a ward unable to hear anything.

Those who participated in the consultation meetings frequently referred to the support received from lipreading classes – once they had found out they existed. *'Lipreading classes saved my life'*. However, the way they are structured (e.g. only offered for a limited 10 week period) and funded varies from area to area, from Council funded courses to those funded by organisations like Deaf Action, and some in which the individual must meet course fees themselves.

There was a strong view that there should be more locally based resource centres (as well as domiciliary visits where necessary) where people could drop in to get help with basic hearing aid repairs/pick up batteries. The current system within Audiology Departments does not permit a drop in repair service, but for people for whom a hearing aid is a lifeline, to have to wait for some weeks before a simple repair can be effected can be devastating. *'I cried all the way home because I could not get help'*

Several times we were told that the type of specialist equipment on offer to support every day living, whilst welcome, was outdated, and varied from area to area; we also heard examples of excessively long waiting times for equipment to be installed, and the wish expressed that this could be streamlined.

All deaf people wished that Councils, the NHS and others had the facility for text messaging using a mobile phone (sms) to enable access, as well as email and BSL interpreted web links.

Some expressed a degree of cynicism that anything would change, as their experience was that funding was not readily available to meet the needs of those who are deaf.

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

Deaf Action offers a range of specialist social care provision; there is no structured automatic referral route from Audiology services to enable it to provide information or offer support to those diagnosed with a hearing loss. There is no clear referral route from Education services. Referrals from other mainstream Health and Social Care providers are dependent on individual assessments carried out identifying the needs of those with a hearing loss, but frequently we were told by deaf people that because they 'looked normal', and people did not know what was available, they were not given the support required. One person told us that she was taken aback to be told that the answer to her problems was for her to move into sheltered housing.

Better dissemination of information is essential, to other care providers and to deaf people themselves, in appropriate formats and languages, and self-referral is to be encouraged.

1.(d) How will you make these changes?

Clear guidance needs to be issued on referral pathways and integrated health, social care and community support. Currently, it is our experience that this varies from authority to authority and at times is dependent on individual relationships rather than structures.

Awareness training for front line staff would improve knowledge of the issues faced by those with a hearing loss and the sources of support available

Support is required from partners in authorities to ensure improved dissemination of information. We are currently working with Audiology services to explore possibilities of fast tracking and direct referrals (our staff are already trained to carry out simple repairs) and have begun discussion with some local authority partners to review current services.

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?

Basic screening for hearing loss should be regularly carried out, and local care pathways involving participation from all key stakeholders agreed and understood

2. (b) Which are the most challenging to put in place?

A commitment from statutory agencies to agree consistency of approach across Scotland and a commitment to awareness training for front line staff.

People with sensory needs have been marginalised from service developments and the provision of resources. Whilst it is often difficult to distinguish funding made available for services for those who are deaf, as they are often subsumed within a physical disability budget, it is our experience that funding restrictions, as well as the low priority given to it, impact on the provision of the required training. Deaf people we consulted all agreed it should be mandatory and carried out on a sustainable rolling programme. It is Deaf Action's belief that it should also be delivered by those who themselves have a sensory loss.

However, to say 'a commitment to the *consideration* (our italics) of sensory impairment being included in generic assessments'is unnecessarily weak. In order to improve services this MUST be done, and appropriate training given to ensure that it is done comprehensively and professionally.

Over the years, services for people with a hearing loss have been increasingly eroded. Financial cutbacks have ensured that services do not reach those in most need or develop in innovative ways. The recent Scottish Government funded initiative between Deaf Action and the RNIB has enabled us to try to reach those who have not easily hitherto benefited from support and information – e.g. people with a sensory loss from ethnic minorities, those who also have a learning disability, or dementia or are diabetic – but unless additional resources are made available, then access to care pathways for such groups will remain limited.

2. (c) Do you think that any key factors have been missed?

There is no reference to the U.N. Convention on the Rights of Persons with disabilities which enshrines recognition of the rights of deaf people in particular to the use of their signed language in official interactions (Article 21, Freedom of expression and opinion and access to information, and Article 30, Participation in cultural life, recreation, leisure and sport)

A number of people highlighted the need for a greater focus on new technology to enable deaf people to benefit more from services (e.g. by the greater use of on-line BSL interpreting, or appropriately adapted GPS alerts for deaf people with dementia); there is little reference to this in the Strategy.

3. 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?

It has not been our experience that it is easy or possible to distinguish the amount of spend on people with sensory needs particularly in social care, and within that group, the amount of spend on people who are deaf as opposed to people who have a sight loss, as recording/statistical information has not been kept in such a manner.

Currently, information recording systems/data collection varies from local authority to local authority, and IT systems are incompatible with both the NHS and each other thereby complicating the sharing of standardised information.

Whilst the spirit of recommendation 6 – to scrutinise compliance with the Equality Act – is commendable, it is not clear whose responsibility this will be, and how it will be achieved.

3. b. Which areas for action will make the most difference and why

Structured screening for hearing loss, registration, and referral to a clear care pathway will enable targeted preventative support to be offered, with statistical evidence of need underpinning service delivery in an effective and efficient way

3. (c) Are there any other areas for action that you would like to see included within the strategy?

People who are themselves deaf or have a sight loss should be involved in all stages of service planning, delivery and monitoring, and resources should be made available to enable this to happen. BSL users in particular have restricted access to information and many hard of hearing people told us how lacking in confidence they felt. The ideal of co-production of services requires preliminary investment in capacity building before it can be achieved, but in order to achieve effective service re-design, it must be prioritised.

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.

Deaf Action has significant experience of providing services to people with sensory needs in a variety of ways. It has directly employed specialist staff to work with people who are deaf across Lothian, and has worked for the past 12 years in co-location with Council partners in the West Lothian Sensory Resource Centre, which was established in 2001. Deaf Action is also an active partner within the Fife Sensory Impairment Service, where other third sector organisations and Fife NHS work with those with a sight loss and complex needs, and has just begun a partnership with the RNIB in joint activity to develop services across Lothian for 'hard to reach' people with sensory needs (e.g. those with a learning disability/dementia/stroke, from ethnic minority backgrounds, or families with children who may be deaf or have a sight loss) It also piloted an

approach to sensory services in Argyll & Bute by the use of staff who worked with both deaf people and blind people, rather than is currently the case, as staff tend to specialise in either working with those with a sight loss, or with those who are deaf, or with those who are Deafblind.

The current models of 'one stop shops' across the country vary in design and quality, and will differ in scope in rural and urban areas; objective assessments of outcomes and challenges need to be further explored. Whilst there are advantages to co-location with other services, particularly to reach the growing demographic of older people with both a sight loss and a hearing loss, there is inevitable concern that this potential for merging of two specialist services may be seen as a cost cutting measure, rather than a measure to improve services to an underserved group of people.

There are inevitably difficulties in providing 'cradle to grave' services; social care staff have to have expertise in a range of areas (mental health, criminal justice, children & families, learning disability, older people), as well as being able to communicate in a different language (BSL) with service users. There is a poor career structure, and no additional funding available to offset training needs.

5. What difference will the implementation of the strategy make

We are concerned that a lack of funding, and lack of a designated lead will make implementation of the strategy unachievable.

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?

More work needs to be done to integrate GIRFEC principles and the work of the Doran review with the Sensory Strategy, and to ensure that specialist knowledge on sensory issues is shared with those working in Children's Services. The original thinking behind the Sensory Strategy did not include children and young people; to have it included at a later stage has not allowed for sufficient time to explore the detail required, in particular with the concerns expressed to us about support for young people at times of transition to adult services.

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?

Whilst acknowledging the importance of resource allocation towards preventative strategies relating to eye and ear conditions, to say there is an 'acceptance of a redirection of resources towards more targeted preventative strategies promoting a healthy lifestyle' disregards the differing socio cultural perspective shared by those BSL users who do not see themselves as having an 'impairment', but regard themselves as members of a linguistic community, and who do not view

their lack of hearing as an issue. For them, issues are poor access to information and services.

There is a need for a skilled and well trained and supported workforce, but little consideration given to the workforce planning required. There is no guidance outlined on the skill levels needed, or the qualifications necessary to carry out aspects of work with those who have sensory needs, or continuous professional development requirements.

There is also a need for agreed quality standards to be developed against which services can be measured and inspected by those with the expertise to do so.