

## 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.

This a difficult question to answer seeing as this is a hypothetical situation, and until it is put into practice then can I make an assessment.

I believe that to have a system and structure in place is a good thing. However, theory and practice do not always go hand in hand as we would like to believe. It is a chain of events and unfortunately the chain is as strong as its weakest link.

In my own experience both as a service user and a professional working in the field of dual sensory impairment, I have encountered far too many, "Weak links". It almost always appears to a combination of a reluctance to share information, have the relevant knowledge of organisations and finally communication breakdown across organisations.

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

Essentially there is a greater need for everyone to understand the different kinds of sensory impairments and the impact upon the individual, how to identify people with sensory impairment and how best to address them and appreciate the different types of communication methods in order to engage with that person. The first step on any journey/pathway should be as stress free as possible.

There is an absolute need for Partnership working to ensure people with single sensory impairments are referred to the appropriate organisations before the onset of a secondary loss impacts upon their communication, mobility and access to information abilities. E.g. a person living with deafness will rely upon their sight to access the world for communication, mobility and gaining information. When their vision begins to deteriorate, this will have a huge impact on their lives. This person will have been with a Deaf society and as the vision worsens they may get referred to a social worker for the blind, but not onto Deafblind Scotland. By all means refer to Blind organisations, but also to Deafblind Scotland. This is the same for the person living with blindness and having the co morbidity of developing a hearing loss. Timely intervention is so important for a person receiving a diagnosis of a sensory loss.

It is absolutely imperative that staff receive mandatory training to ensure all staff from specialist down to front line staff attends Sensory awareness training and that the training package includes all 3 strands of Deafness, Blindness and Deafblindness, and not delivered as singular training.

I have great concerns about how the different types of sensory impairment will require different responses. Who is out there to both identify and signpost those with dual sensory loss to specialist service providers?

We need "Sensory Champions" in every local authority, health organisations or care

providers- a point of contact that is specially trained in Dual Sensory loss. A minimum qualification should be to have the Deafblind Diploma.

I have to ask, "Is the referral process robust enough to ensure dual sensory people are channelled to the appropriate organisations?" There needs to be a greater awareness of whom to refer to, which organisations are out there to ensure a better understanding of a diagnosis, who to seek help from regarding support, counselling and rehabilitation. All too often, the specialists do not know who is out there to give that vital help and have sent the patient to the wrong and inappropriate organisation/support group. Often there have been cases where the specialists do know what happens once they have been referred on.

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

N/A

(d) How will you make these changes?

N/A

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?

As I have alluded to in the previous question, communication between all departments and organisations is imperative.

Early intervention is a vital requirement to ensure people with dual sensory loss get the timely and appropriate strategies in place.

More work needs to be done around Partnership working between Blind, Deaf and Deafblind organisations. We can all bring, "Added Value" to each other, but only if they are all willing to work together.

Funding should not be allocated to the larger organisations.

Direct referral to services offered after diagnosis needs to be addressed, the system at the moment is still biased for the major providers such as the Blind or Deaf organisations (Social workers for either) but very little in the way of direct referrals for Deafblind services. Frequently single impairment organisations are steadfastly refusing to share or refer on when individual becomes dual sensory impaired, and at Deafblind Scotland we get many members who have become severely dual impaired over a long period, which makes it more difficult to teach them alternative communication and rehabilitation skills.

On the subject of data collection, there is a need for a single point access data base system and it is essential that a system is put in place to identify dual sensory loss and flag up the appropriate services, rather than refer only to Deaf or Blind organisations, but to refer to Deafblind Scotland for those with a dual sensory impairment as well as to the relevant Deaf or Blind society as applicable. There are software packages within the doctors practice/health practices such as VISION and EMIS which have this facility, although surprisingly a large number of practices are aware of this. This should be compatible with a national database.

There should be more joined up communication between Audiology and Ophthalmology as well other departments working, for example, in gerontology, diabetes, stroke units etc. A single shared data base could flag up and correlate all the information and share as appropriate.

The strategy will only be as good as the number of professionals who are trained to have the specialist knowledge of Sensory impairments, particularly encompassing dual sensory loss. Identification and the referral process is so important for early intervention and ensuring that the person will be treated with respect and dignity they deserve.

The system will only be "Seamless" if everyone is fully aware and compliant with others in the group and "fully partnership" working together, otherwise it will not work and some groups such as the "Dual sensory" will become further marginalised.

Sensory Impairment should be inclusive of all 3 strands – Deaf, Blind and Dual sensory at every stage of observation/assessment and not a single impairment as often the case.

Basic screening should be as read. At every visit, consultation, check-up there should be checks on sensory functionality and this is monitored on the shared data base to an get early diagnosis as possible.

I am not happy about local care providers being responsible for meeting outcomes; it should also include the national providers.

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

I believe the most challenging task is to ensure that all sensory groups will commit to the agreement of a consistent approach across Scotland. I think that many organisations will not talk to each other and be prepared to share information from a local level to a national level. There is a lot of history, culture and political interests at stake between single sensory organisations that needs to be recognised.

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

I think the inclusion of having “Sensory Champions” who have attained the recognised qualifications and are striving to collectively achieve specific outcomes equally across Scotland.

There is no mention of what the achievable outcomes are, which in turn need to be agreed as to what is actually being measured and how this is to be monitored.

Who is ultimately responsible, and can anyone be held accountable?

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?

#### Recommendation 3

It will be very difficult to establish sensory awareness training across staff in health and social care settings mainly due to the fact it is not mandatory and also due to the fact the staff are often far too busy and it is too costly to take staff away to attend training. There needs to be a provision to allow staff to undertake training. A good way would be to include compulsory sensory awareness training at training colleges/hospitals before they enter the field of work. The training should also be part of induction training for staff working in community nursing homes and for O.T staff etc. Indeed wherever staff are coming into contact or working with sensory impairment should have mandatory training for example training colleges for students entering the field of optometry and audiology would be an excellent starting point.

As I mentioned before this sensory training should be covering all 3 strands of deafness blindness and deafblindness equally and ideally by someone with a disability.

#### Recommendation 5

Another area I believe will be fraught with difficulties. There will be a reluctance to divulge or share information between agencies both at local and national levels. All too often through the course of my work I met with many sensory organisations that told me;

“they could identify a 100 people who fit the description of deafblindness”,

“ We have lots of deafblind people that we know about”,

“I know a number of elderly people who are wearing hearing aids and finding it difficult to understand me”. There were a number of local authorities that said similar things, yet when we look at the referrals from these areas we have very few!! As a point of fact 50% of our referrals are self referrals from people who have picked up our leaflets in various hospitals and Health practices.

It would be interesting to know who will be overall responsible for ensuring that all the service providers and organisations will work together.

(b) Which of the areas for action will make the biggest difference and why?

I believe and sincerely hope that the compliance with the Equality Act 2010 will have an impact on the dual sensory group.

Under this act communication support is available as a right – not just BSL but also Guide/Communicator support to be provided Scotland wide. At present BSL is a right and funded for the Deaf population, but when that person becomes blind and unable to use BSL, they are no longer eligible to be funded. “Lose the sight, lose the right”, hence a right for Guide/Communicator support.

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

I would like to see a recommendation whereby the Guide/Communicator support recognised.

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.

My own experience of having a dual sensory impairment (Usher syndrome type 2) and working for Deafblind Scotland, and recently in a Participation project funded by the Scottish Government that looked closely at One-Stop Shops has given me an exclusive insight into the provision of sensory impairment service at all levels across Scotland. I have answered the previous questions based on this experience and knowledge.

I really believe that one-stop shops are the future, but unfortunately, until organisations are genuinely willing to work together in a joined up manner, are willing to share knowledge and include all sensory organisations working collectively together then we are not going to be able to move any further forward. As mentioned previously there are huge issues around history, politics, traditions and cultures within the sensory organisations that will prove difficult to overcome.

Awareness training for staff at all levels is not always apparent, especially across all 3 strands of sensory impairment. There is a lot of training of single impairment provided by both the deaf and blind organisations but hardly any combined sensory awareness. In order to make all health service venues more accessible and inclusive, all staffing should have knowledge of all the different kinds of sensory impairment.

On a number of occasions I have entered venues (not necessarily one-stop shops) and found the Loop system not working or even supplied. I have met with staff who are not aware of, nor how to switch on Loop systems for the hearing aid users.

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

If all the issues mentioned were to be addressed, then should I need to visit any health service provide then I would be entering an accessible and inclusive environment which in turn provides me with a stress free consultation with whomever and I am seeing. It would be fantastic to feel I am treated with the dignity and respect that everyone is entitled to.

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?

N/A

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?

There is no mentioned of projected/predicted figures for the Deafblind/Dual sensory impaired. Concurrently as demographics change in relation to longevity then the numbers will grow correspondingly too.

I am not comfortable with the need have four types of sensory impairments and to categorise Deafblind separately to Dual Sensory? I think that to have one descriptor called Dual Sensory loss and to have severe deafblindness as a degree of Dual sensory loss would be far more sensible. At the same time we should be prepared to use the terminology interchangeably (to recognise the hard work put in to recognise deafblind people, see below). Just as the Deaf have many levels of deafness ranging from hard of hearing to profoundly deaf. And as with Blind, ranging from partially sighted to no light perception. Then so too for Dual sensory and allows for a spectrum of different degrees of combined sensory loss as for the other 2 groups.

The Scottish Government's "Generic Core Data Standards, Scottish Social Care Data, Standards Manual, Version 2.0, August 2005, page 102-3, defines combined sight and hearing loss,

"Persons can be regarded as having combined sight and hearing loss (deafblindness) if they have a severe degree of combined visual and auditory impairment resulting in problems of communication, access to information and mobility. There are many routes to deafblindness which can occur at different stages of people's lives, as follows:

- both of the impairments resulting in deafblindness have been present from birth. A person who is deafblind from birth is likely to have other problems such as a Learning Disability, physical disability etc
- only one of the impairments has been present from birth and the second impairment develops later in life (eg. certain forms of Usher Syndrome)
- neither impairment has been present from birth; they both develop later in life.

The terms people might use to describe themselves are:

- deaf with a visual problem
- blind with a hearing problem
- partially sighted, partially deaf

- having Usher Syndrome
- deafblind
- dual impaired
- dual sensory impaired
- hard of hearing with sight loss
- a hearing aid user with a sight problem
- blind and hard of hearing

Who is actually going to be doing the monitoring and reviewing of this strategy?  
What exactly are the measurable outcomes and how are these to be measured and against what? Do we already have figures to be met and achieved, something I foresee being problematic especially in light of the rapidly changing demographics.