

## 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.

Notwithstanding the difficulty of reading the given care pathway for a service user affected by sight loss, I would like to encourage incorporation of the sight loss pathway developed by the Vision 2020 working party considering the future of rehabilitation. This pathway is incorporated in the revised UK Vision Strategy and will also be represented in the revised Scottish Vision Strategy that is going to be produced later in 2013. As a service user, the value of this pathway is that it has been developed following consultation with service users. Consequently it seems a more assured method of making a difference to the lives of people newly diagnosed with sight threatening conditions, or already living with some form or degree of sight loss.

Some of the key factors that make this pathway appropriate are:

- It recognises the benefit of emotional support at the time of diagnosis and at key points on the life long journey of sight loss.
- It reflects and affirms other developments in the support of people with sight loss, such as Seeing It My Way and the Scottish Vision Strategy.

I am absolutely sure that a suitable pathway will make a difference to people coming to terms with and living with sight loss. If this is applied consistently across all stakeholders in the journey the person at the centre of the process will have greater confidence that the necessary interventions will be applied at the time when they can make the most difference. In this context we need to bear in mind that some medical interventions are time critical if they are to preserve all or some of a person's sight. It also reflects that each person will react differently to the news of a sight threatening condition, and will need support at different times and at different levels to remain as independent as possible.

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

The most critical factor in ensuring that services and support meet my needs, and those of all blind and partially sighted people in Scotland, is to listen to what they say. An extensive consultation has already been

undertaken with blind and partially sighted people to determine what they are looking for. This was published under the title Seeing It My Way. It takes the form of a series of outcomes that people affected by sight loss expect. It ranges from being able to understand the condition that is causing the sight loss, through being able to live an inclusive and independent life in the same way as their peers, to being able to access employment or leisure. Seeing It My Way has been adapted to reflect the needs of those with hearing loss as well as sight loss and was included in submissions for the drafting of the sensory impairment strategy. It does not seem to have been retained in the draft strategy which means that the needs of service users have been lost. I would urge an overt statement of the standards that can be expected by people living with sight or hearing loss, expressed in the terms of what is evidentially important to them.

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

(d) How will you make these changes?

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?

At present there is no consistent understanding of the role of habilitation workers (for children's services) and rehabilitation workers (for adults). The Welsh Assembly has recognised this and is working towards a professional standard for workers in the profession. I would urge the Scottish Government to follow the Welsh route, agree a professional standard and encourage its adoption by agencies responsible for its delivery. Many local authorities will contract the service delivery to the third sector. The providers may well follow a high professional standard as they have a more intimate knowledge of the needs of service users with a sensory impairment than a generalist in social work will be able to develop. But incorporating the professional standard in a service level agreement will reinforce this.

The strategy creates a requirement for mandatory sensory awareness training for front line workers. This is positive and is certainly to be

encouraged. What needs to be clear is who is a front line worker? This needs to be given the widest possible definition in order that the needs of people with sensory impairment are fully met. For example, an architect is a front line worker as the buildings they design will be used by people with sensory impairment; a web site developer is a front line worker as the sites they produce should be usable by people with sensory impairment, possibly with the support of access technology.

It should also be a stated intention that the mandatory training be delivered by service users. Whilst others may be able to learn the script to deliver this kind of training, only those who are living with it day by day can bring it alive for the delegates. I would also urge an experiential training approach be encouraged. DVDs and on line tools will inform delegates of the facts. However, everyone underestimates how hard it is to live with a sensory impairment, even the medical professionals responsible for treating affected patients. Only by having the chance to talk about it with service users and experience some of what they have to go through in every little way will people begin to understand, appreciate and therefore respect people with sensory impairment.

This does not mean that training is to be handled by volunteers. It is still important that a quality standard is achieved. The positive benefit of requiring user delivered professional training is that a group of people who might otherwise have found it difficult to obtain employment (75% of blind people of working age are out of work) will become productive members of society, replacing out of work benefits with income and tax revenue.

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?

(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?

The strategy describes itself as covering the needs of people with a sensory impairment, from cradle to grave. I'm concerned that there seems

to be very little reference to the needs of children beyond acknowledging that needs start from the cradle.

The Vision Strategy pathway and Seeing It My Way are unashamedly adult based solutions. A children's pathway is under development. Whilst this may not be ready for incorporation in the strategy, it would be helpful to refer to a specific pathway for children once it is agreed. Seeing It My Way does acknowledge the needs of children and young people, for example, with an outcome of being able to access education, transition services and entry to employment. All this needs to be a part of the sensory impairment strategy.

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.

As a service user with sight loss, I have felt that the onus for accessing services has been entirely my responsibility. If I don't ask for something, I don't get it. But most people affected by sensory impairment will be experiencing a life crisis with no past experience to fall back on. We don't know what is available to ask for. Consequently many people will become isolated. With isolation come risks of emotional difficulties, stretching from a lack of confidence to leave the house, to severe mental illness.

It is essential that there is proactive case management built in to the strategy. At the point of first diagnosis people will need support that is not currently provided by medical services. The loss of a sense is akin to bereavement. The shock means that information will not always be heard at this time. So return visits will be important. It is also something that will last a lifetime. The solutions and services that may be appropriate in first coming to terms with sensory loss will not necessarily last a life time. The condition, possibly mitigation of its impact, opportunities for treatment, the life needs of the service user and the environment we live in are all dynamic factors and the support that goes with them must also be dynamic.

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

One of the outcomes in Seeing It My Way is that I will receive correspondence in my chosen format. It will be clear that in order to complete this consultation I have had to undertake significant editing of

the response form. If the strategy takes on board the consultation that has been undertaken to understand what people with a sensory impairment want as outcomes from service providers I can imagine a Scotland in which I feel I am a valued and valuable member of society. If the opportunity to incorporate what I, and those like me, is missed, the strategy will not make a difference. I will still have to fight for access to an inferior quality of life in Scotland to my peers.

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?

See comments on the cradle to grave approach above.

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?

With an aging population, there are going to be an increasing number of people affected by dual sensory loss. Creating a single sensory impairment strategy is beneficial as it will meet the needs of those people through a single route. However, we need to remember that many with dual sensory loss will have acute impairment of one sense and more mild symptoms in the other and much of the younger sensory impaired population will only display loss of one sense. Consequently there is a value in a joint sensory impairment strategy and the commissioning of joint sensory impairment services. However, we must not lose the specialism of support for a single sensory impairment. People who are blind or deaf may fit under an umbrella of sensory loss from an administrative perspective, but will not have much in common with each other. For example, a deaf person can drive, but a blind person has severe mobility needs. A deaf person may struggle with face to face or telephone communication, but will probably find electronic communication easy, whereas a blind person will find audible communications reasonably straightforward, but will struggle with paper or on line correspondence.

We have many things in common, but a lot that makes us different. A degree of segregation within an integrated structure will be valuable.