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.

Other than through periodic contact with the NHS and certain voluntary organisations, I am largely unaware of specific services and information that may be available locally. What is unclear from the proposed pathway is whether or not this is a simple structure 'tweaking' of some elements that currently exist, in which case there is very little to get enthused about (my example below outlines my concern). If it is a genuine attempt at real improvement, then perhaps it should at least be viewed as a welcome first step to putting in place a complete care framework. I would hope that firm partnerships to assist early diagnosis through to lifetime care support and signposting to services for sensory impaired people at different stages of sensory loss, will be an actual deliverable.

By way of example, at the time of clinical diagnosis of my visual impairment, initial signposting to specific assistance and possible entitlements (concessionary travel etc) was provided by RNIB. I was fortunate to have been asked by an RNIB care worker if I had considered using a Guide Dog and further down that line I am now a Guide Dog owner. However, what was clear to me at the time, and I still believe it to be the case, was that there was no real clear or integrated partnership working between and across either the statutory care or voluntary sector providers. The availability and quality of sensory impairment information has improved through time. But, accessing and communicating information and, more importantly, what type of assistance might be available, what to expect from statutory and non-statutory care providers, and where and when to obtain assistance as your impairment progresses, is extremely haphazard and patchy. Reaching a wide sensory impaired populace is undoubtedly a challenging task. Post clinical diagnosis, most information is obtained through the voluntary sector, and large scale changes to statutory provisions via Governmental news. My reason for this brief story is to recount what might currently exist, albeit at a rudimentary and possibly in some case informal level, that can be built on. Clinical diagnosis and referral between NHS health professionals already exists. What is clearly missing is a real integration to involve both these NHS professionals, the local authority, and voluntary sector expertise at an early stage following that initial diagnosis for on going assistance and direction for the individual, and family, concerned.

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

There is unlikely to be a single service provider to implement all aspects of the pathway. Indeed not every service is appropriate to every individual, but knowledge of services or options that are available can aid an individual's choice in care and assistance. At present, there is no mechanism in place that can identify the numbers and needs of individuals with a sensory impairment within a local authority area. This should first be robustly established to identify the local scale and scope of care need, and thereafter be subject to regular review. Clear linkage between clinical diagnosis and local statutory providers needs to be established to ensure quick follow up action to relevant information and care support where required. This should be tracked though the lifetime of the individual so that assistance can be offered as circumstances and sensory loss change. Partnerships on a more formal basis between and across statutory, third party, and voluntary sector providers must be established, and that duplication of effort between similar providers is avoided as far as practicable. Local Authority and other statutory provider partners should, nevertheless, be fully aware of available services provided by voluntary sector providers, even though the predominant service gap in provision may lean towards one preferred option. [By way of example, there are a number of charities providing assistance to the visually impaired community, each providing a differing service and meeting a niche need amongst their users. For a number of reasons owning a guide dog is not everyone's ideal, some people prefer the use of a guide cane, but knowledge of both can help an individuals right of choice]. More is required in training local statutory providers in assisting sensory impaired individuals, and the expertise of the voluntary sector should be utilised in partnership to help bridge this gap. Clear contact information relating to locally available services, assistance, organisations, and entitlements, from a single authority/portal would help diminish confusion on 'who does what' for individuals seeking more information.

I believe that unless these basic steps are made, then service provision currently experienced will continue to be patchy and inconsistent.

I didn't ask to loose my sight and I value my liberty and an independence as highly as every other person. But I have had to come to terms with the fact that I do need to ask for some assistance at various times. Presently, knowing where to go for information, 'who does what', and what to reasonably expect by whom, can be confusing. For some people, isolation may also be a factor and simply being periodically contacted by a local care provider and informed of improved or available assistance or local groups may help to improve their quality of life.

(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?

See my comment at (c).

As to those that have been listed in para 6.7, a commitment to generic assessment would help identify early sighs of sensory loss and trigger some form of care provision.

Clinical information and long term prognosis is already provided, what is required by the person with sensory loss is information on what assistance might be available, by whom, what to expect from service provision and assistance, and who will contact them or if they themselves need to make initial contact. Initial diagnosis can be devastating for both the individual and close family members, quick follow up contact from relevant local authority care providers and specialist organisations may help in regaining an individuals confidence and independence and focus for the future.

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

Information gathering and Information Sharing across a range of statutory and non-statutory partners and seeking consent from individuals with sensory impairment. Notwithstanding technical operational issues between disparate data systems and organisations, obtaining and maintaining ongoing individual consent and defining what information is required and to be shared is a high risk factor.

Much of this consultation is focused on statutory providers and a drive towards consistency in approach. It is unclear if this is meant as local or central, who would determine what is or isn't good practice, how non-statutory providers fit into this framework, and who would monitor services delivered to individuals. I am concerned that a great deal of time will be spent on developing the 'Care Path Framework' with little or no practical service delivery to individuals with need being taken forward as a deliverable.

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

Yes.

(1) A clear commitment to quick and quality front-line service delivery for the person with need. This should be stated as the primary driver and outcome. The specifics detailed in para 6.7 are functional 'back-room' requirements necessary to make quality service delivery. As previously stated, this consultation appears to focus heavily on statutory provision and the Care PathwayFramework. This is very process driven and, in its current guise, looses sight of the primary goal of service delivery to individuals. My concern is that a disproportionate amount of time, effort, and cost is incurred in establishing a Care Pathway Framework document at the loss of service delivery to those requiring assistance or care.

(2) The Care Pathway Framework should be a dynamic document that is subject to change (by agreement with parties concerned) to take account of improved practices, services, information, and new providers. In this way, scope can be built in to established early partnerships and agreements while ongoing evaluations and implementation processes and policy developments can take place separately. This would help to identify and implement 'quick wins' for service delivery over a shorter timeframe. [As an example, basic staff training for frontline staff on assisting people with sensory impairments, the use of public buildings (libraries, council offices, etc) to provide basic 'Ones Stop Shop' information and contact details of local/national voluntary sector assistance as well as lead local authority staff contacts].

(3) A commitment to real partnership working between and across all statutory, third party, and voluntary sector providers. There is a distinct focus on statutory provision, for good legal cause, but the Pathway makes no impression on the potential inclusion of voluntary (or Third) sector provision. The current vacuum in statutory provision for sensory impairment has been taken up by a number of voluntary organisations over many years. These voluntary organisations have expertise in the specific areas of sensory care that should be harnessed by the statutory sector. Importantly, more and firmer working partnerships between statutory and non-statutory voluntary organisations for delivery of training and services should be established.

(4) Section 3 provides background and section 5 touches on some outcome focused deliverables, but these appear to be lost the in primary focus of delivering a Pathway Framework. The Care Pathway Framework should look again at some of these, such as independence and the individuals choice over type of care/assistance that is appropriate, and incorporate these. Confidence building and emotional well being and support should also be included. For many, initial diagnosis and 'what happens now' can be as emotional as a bereavement for both the individual and close family. Initial support for both may be required and this is missed in the Care Pathway Framework.

(5) More generally, there is a deficiency in trained 'Habilitation' support care workers in both statutory and non-statutory bodies. The Care Pathway Framework needs to recognise and address this issue, and that duplication of require resource should be avoided (as far as possible) to allow for the correct recruitment by the correct organisation. Where a specific shortfall is identified in meeting local provision and partnerships are established, I see no reason why partners could not assist each other in helping recruit new staff for a partner organisation. As an extreme example, it would be a mistake for a local authority to recruit and train its own staff as guide dog, guide cane or 'habilitation' trainers. The need for such training exists, but local partnership working in a recruitment drive to meet an identified shortfall may help reduce duplication of effort and maintain local end delivery to individuals.

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?

See comments at 2 above.

Data gathering and sharing will be problematic and potentially time consuming, yet necessary to truly understand the scale and range of needs within local communities/areas.

A robust audit is required if a start benchmark position is to be established and thereafter used for *inter alia* comparison. However, the focus of Requirement 1 on current spend and realignment only is flawed because it makes a presumption that current spend in some way is meeting demand. It is not, and many local authorities do not have a specific budget or service program in place to tackle sensory impairment issues other than accessibility requirements through DDA etc legislation. The 'slack' in spending is borne by the voluntary sector, and without whom many sensory impaired people would have a lesser quality of life. The Scope and Purpose of any audit must, therefore, be fully considered.

In addition to overall spend as currently proposed in Recommendation 1, it is essential to establish: who and where the sensory impaired populous are across Scotland, (including those who are not currently known through established routes); the range of impairment and assistance currently provided; what actual demand is currently not being provided; and spend specifically made by local statutory providers in sensory impairment service provision. I have a real concern that the inclusion of the voluntary sector in overall spend together with the audit aim of realignment of statutory spend could be construed to the effect that, "the voluntary sector already provide care through charity, therefore, no new budget or provision support is required through statutory providers." This is a discussion I hope all key stakeholders will have.

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

Establishing a system that treads people with care and dignity and provides quality assistance at differing stages of their life and often worsening impairment. This is currently missing and tends to be haphazard for those who often need a little assistance at different stage to refocus and regain confidence.

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

As mentioned in previous sections, greater prominence in the strategy to the primary outcome of service delivery to sensory impaired people.

Real commitment from Central and Local Government to establishing effective partnerships with established voluntary sector expertise.

Clearly defined timetable and commitment to actioning the strategy and early implementation of a recast Recommendation 1.

A rethink of the target group in Recommendation 3. I believe the target group should in fact be people in the age range 17-35 years. For many of us as we have aged, we have developed coping strategies, often evolved through osmosis as well as some early life training. However, there are very many bright sensory impaired young people who require some assistance and training to help them into the workplace. The same basic sensory awareness training for health and social care staff targeting this younger group could be applied when caring for older people. But by including a younger target audience, the care providers will have started what could be a longer term assistance program with these individuals. This is surely in keeping with some of the main objectives of the Strategy as stated in paras 4.1 and 4.2.

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.

See earlier comments.

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

It too early to say, but I would at least expect to hear from my own local authority on what action they are taking locally and what partnerships are being put in place.

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?

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?