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.

People responding through Fife Sensory Impairment Centre User Panels have a wide range of sensory impairment and very different experiences of services. Contributors had little experience of care pathways and the effect on service provision.

Comments were generally positive however. The “Single point of access” was clear and the idea that once on the pathway there would be a clear progression to other sources of assistance was welcomed.

People newly diagnosed with sight or hearing loss commented that at that stage they did not know what questions to ask and hoped that the pathway would help them access information they did not know they needed.

Those with dual sensory impairment often have to deal with numerous agencies and it was hoped that this would diminish if the care pathway were to be implemented.

It was hoped that those experiencing dual sensory impairment would be less marginalised than they feel at the moment. The comment was that those “on the edges might become more mainstream, as it were.”

People were generally positive about services being for all those with sensory impairment instead of being under different headings.

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

Everyone responding through Fife Sensory Impairment Centre User Panels emphasised the need for monitoring.

At all stages panel members thought questions should be asked such as “Did you get what you needed?”, “was it any help?” and “What else do you need ... and what about you hearing/sight”.

Accessing information for people with sight loss can be very difficult. People feel bombarded with information which all takes a long time to access and understand. Panel members felt the information given should also be monitored along the lines of, “...and have you been able to use all this information? Has it helped you in any way?”.

For people with a hearing loss, face-to-face interviews can be stressful

(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?

People responding through Fife Sensory Impairment Centre User Panels were clear that staff training was of paramount importance although it is the last point of para 6.7.

Point 4 of paragraph 6.7 was contentious.

It was felt that as most people suffering from sensory loss and dual sensory loss were aging their dependency on well trained staff was high.

It was felt that at the moment staff knew about deafness or blindness but knowledge of the effects of dual sensory impairment was lacking.

Concern was expressed about who would be trained.

In general it was felt that if staff are 1) trained, 2) aware, 3) know what to offer and 4) have time to listen then “One Stop would be better as you would only have to tell the story once”.

Confidence in the abilities of the person who was the first point of contact is crucial for the person experiencing sensory loss. Hearing and sight loss can be caused by many things and are sometimes symptoms of more serious medical conditions.

It was felt that if indeed the first person a client saw on diagnosis was better trained and informed across a range of provision that this would be a positive step forward.

In Fife it was felt that blind and partially sighted people already have an efficient pathway operated through Fife Society for the Blind and it was hoped that the Scottish Government Sensory strategy would enable people throughout Scotland with either sight or hearing impairment to enjoy a similar service.

The need for a register of people with varying degrees of sensory impairment was acknowledged particularly by those who are hard of hearing. There is a register of people who are blind and partially sighted and deaf BSL users can register with the police who will co-ordinate emergency assistance of many sorts. Hard of hearing people feel that their needs are not met and that they are left very much to their “own devices”. Indeed, many hard of hearing people use private services where assistance stopped with the purchase of a hearing aid.

Simple referral routes, registration, screening and single points of access would all improve services for those experiencing sensory loss and would be welcomed. The

commitment and training of staff is crucial to successful implementation.

It was felt that GP's already ask about diabetes and blood pressure on a regular basis even when they are being consulted about something else. To ask about sight and hearing loss could be approached in the same way.

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

People responding through Fife Sensory Impairment Centre User Panels felt that most of them would make the first contact through their GPs. Panel members experience of GP practise was varying. Having diagnosed a hearing loss or sight loss the GP would then make an appropriate referral and possibly it was at that point that the trained member of staff should give information rather than actually in the GP surgery. It was felt that there was little time in a GP surgery to discuss things in depth. In addition although panel members already suffering sensory deprivation were comfortable with regular doctors they were not comfortable with locums or other GPs, not their own, who would not understand their communication needs.

People with sensory impairment need information in a variety of formats such as Braille, large print, audio CD, DVD etc. It was felt that providing this would be a major challenge. Although not all formats would need to be held at every point of contact, information should be available for the person requiring it, in their preferred format, within a week.

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

People responding through Fife Sensory Impairment Centre User Panels felt that referral for post diagnostic support was important. Many people needed support for the emotional side of accepting and adjusting to, sensory loss. Information in itself was not helpful unless targeted at individual need. This is especially the case for those who experience sight loss where much information is written. It was felt that without the time to explore theses feelings in an empathic atmosphere, people would not be able to engage with other areas of the pathway.

"...when I was first referred [they] offered me all sorts of things that might be suitable somewhere down the track but I really needed them to listen to what I needed now. I wanted to make the most of the sight I had but be prepared for the fact that it might become worse".

"...the adjustment and support you need to come to terms with your condition and what is happening to you" should be a separate step in itself.

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?

Recommendation1.

People responding through Fife Sensory Impairment Centre User Panels were concerned about the money that would be needed to commission the pathway and the commitment to continued funding to see the changes through. It was felt that a redistribution of money might reduce services in other areas.

Recommendation 2.

People thought that this should be quickly implemented as there are already a number of screening programmes undertaken at key points in peoples' lives.

Recommendation 3.

All groups were concerned that staff have the right training and knowledge not just "an awareness". Panel members thought that getting the pertinent information to the right person right at the start would be challenging.

Recommendation 4.

Blind and partially sighted panel members were happy with the integrated services they get from Fife Society for the Blind. Panel members thought that it would be most challenging to get Deaf and hard of hearing people the same services as blind and partially sighted people.

Recommendation 5.

People with sensory impairment already face barriers to everyday life which legislation does not address. For instance hearing loops are a simple thing to improve the life of many a hard of hearing person. However hearing loop technology does not keep pace with hearing aid technology and there is an unwillingness to upgrade hearing loops after their initial installation. Hearing loops installed are often of the cheapest to comply with legislation. Staff do not receive training in how to use them and they are often not working properly.

People with other form of sensory impairment face daily barriers to living, more emphasis on ensuring compliance would be useful.

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

People responding through Fife Sensory Impairment Centre User Panels had very varying experiences of service. Some were content with the service they received and were unable to predict how the service could be improved.

Pertinent and accessible information made available at the point of diagnosis would be most helpful. Many panel members cited the difficulties of getting the right sort of information particularly at the start of their journey.

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

People responding through Fife Sensory Impairment Centre User Panels felt that people with sensory impairment had very individual needs, they would like the individuality to be 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.

People responding through Fife Sensory Impairment Centre User Panels felt that blind and partially sighted people already had an efficient pathway in place for them; this goes from diagnosis to the support of Fife Society for the Blind with the low vision clinic, equipment, social work and support groups.

People who are hard of hearing thought that there was very little for them compared with that for blind and partially sighted people. Although the Deaf Communication service (Fife Council) will fit and install loops the service is not promoted or widely used.

People who are hard of hearing felt that theirs was a hidden problem and people who are Deaf are more recognised that those who are hard of hearing.

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

People responding through Fife Sensory Impairment Centre User Panels gave examples of the amount of duplication that happens at the moment and the amount of information they have to find out for themselves. The hope of the groups was that the strategy who improve this with more streamlined access and more accessible pertinent information in appropriate formats.

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?

People responding through Fife Sensory Impairment Centre User Panels were unable to comment on this.

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?

People responding through Fife Sensory Impairment Centre User Panels generally found the See Hear document difficult to access and difficult to comment constructively on.

The predominance of on-line information and, indeed, the on-line consultation of this document was difficult for elderly people suffering from sensory impairment to access. Some do not have computers. Some had to stop using computers because of sight difficulties and Deaf BSL users found the English impenetrable. It was only the hard of hearing group, if they were computer users who felt comfortable on line.

Panel members commented that with so much change at the moment [PIPs, SDS, council cutbacks, bedroom tax, it was difficult to look too far into the future.