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.

There was a broad approval of the strategy amongst the service users, carers and families although some concerns were raised as to how this would be implemented.

People felt that it was clear and appeared a quicker, easier approach. There was a strong theme of people wanting services to listen and be empathetic to their situation. They felt that it would be beneficial if services had a joined up approach and were able to share information, especially when the needs were more complex. This would ensure that people would not have to repeat their stories all the time. There was general support for staff training so there was a better general awareness of sensory loss across services.

Costs were highlighted and the concern that with reduction in budgets, services are reducing rather than increasing e.g. respite care. Some told stories of budgets being spent to meet the needs of the larger number rather than one child with sensory loss. In light of the current economic situation, could the strategy be implemented?

A concern that by merging hearing and vision loss together, the specialisms would be lost and that dual sensory loss would be missed all together. How could we ensure that that would not happen?

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

Some concerns were raised about screening, saying it was good to pick up sensory loss early, but that it had to be done in a sensitive and supportive manner as not everyone's experience was positive.

Information for service users and their families and carers is essential. It was suggested that everyone should be given a "road map" which includes the individual's rights, the services that are available and contact details. Many felt left to find these things out for themselves.

The idea of one point of access or one stop shop was seen as positive but for many people living in Dumfries & Galloway the geography and transportation system makes this very difficult to implement.

However people did want to be involved in the discussion and implementation, working with services to ensure the best approach for Dumfries & Galloway.

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

There was a consensus of support for the aspiration of the strategy with positive comments around standardising the approach, partnership working and clear lines of responsibility.

The most frequent theme amongst professionals was understandably costs. These costs included:

- mandatory training at a time when it is challenging to meet the current requirements
- cover required for staff to release them for training – costs and availability
- taking on additional screening responsibilities when current services are stretched and skilled staff are scarce.
- the cost of implementing change.

Other concerns raised were the complexity of sharing information across agencies when computer systems are not compatible and there are concerns about compliance with data protection law. There was a suggestion that the Health Passport model should be extended to included sensory loss or consent forms for information to be shared and advance notice given to services of sensory impairment. Services rely on the patients telling them important information and if they do not do this, then it is difficult for professionals delivering the service.

(d) How will you make these changes?

The geography of Dumfries & Galloway is challenging with a large, rural and isolated community and poor transport links across the region. This impacts on the cost of a service and the capacity to deliver. Some front line staff questioned how they fitted into the referral pathway if their remit was wider than sensory impairment. How would they ensure their knowledge and skills were up to date and beneficial to the people they worked with?

There would need to be greater awareness across all services with regard to sensory impairment and referral pathways would need to be simple, clear and widely publicised. To achieve this we would need sensory awareness training, possibly an accredited training package that was delivered at the same level across the region. This however would need to be monitored and supported and takes us back to the first point which is costs.

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?

a) Which of the key factors are most important for a successful pathway?
It was difficult to get a consensus of amongst the group about which factor was the most important therefore I have taken each one and reflected the comments about this.

Clear referral routes – Amongst professionals this was highlighted as a priority and there was a requirement for clear identification of the key people in the area. There is a different approach in children and adult services which is confusing.

Recording information on sensory loss – This was not highlighted as being important however in the other questions there was a theme that services should know before delivering the service that someone has a sensory impairment.

Person centred care solutions and sensory impairment being included in assessment – This was mentioned by some service users and carers although with reference to personal experience. A lack of understanding of their condition has led to frustration, inappropriate treatment or responses and poor experience of the service. Several people highlighted that people with a sensory impaired people should be totally involved.

Sensory Impairment Screening – This was mentioned by professionals and service users with all acknowledging that this would be a positive step. One suggestion was screening when going into secondary and again at the age of 50. Some professionals highlighted that uptake of screening can be difficult but that there should be a stronger preventative message.

Single point of access – Although this approach was acknowledged as good, there were a number of concerns about how it would work practically, how information would be shared, would this become the gatekeeper and it would need a cultural shift to make happen.

Local sensory impairment care pathway – There was some discussion around this with people wanting to be involved in developing but also concern about losing the specialism of each impairment. There was again discussion about sharing information and raising awareness of sensory loss and the steps e.g. equipment that can assist.

Consistent approach across Scotland – This was not highlighted in any of the groups.

Staff training – This was a popular theme across all the questions with an acknowledgement by everyone that it would be good but a concern about costs and implementation of this.

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

Again a mixed response but the following points were highlighted:

- Single point of access which exists for children but could it work for adults?
- Communication with the IT, cultural and organisational difficulties between the statutory, private and third sector agencies.
- Training with costs, practicalities and delivery an issue.

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

Education has been missed out of the strategy but this was highlighted by Angela Bonomy in her presentation.

There is also an issue of governance and who would monitor and oversee the strategy ensuring best practice and working within policy and procedure.

There was no mention of the impact of sensory loss on people's mental health and the strategy would be stronger for a link into this area.

Lastly the lack of opportunity for people with sensory loss to develop skills e.g. sign language

One group felt that there should be a stronger link to Self Directed Support as this is having an impact across Scotland.

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?

The biggest challenge to implementing any of the areas of action is funding and resources. This was highlighted by all the discussion groups and by service providers and service users alike. Funding and availability of skilled staff and resources across an extensive, rural geography make any area for action difficult to implement.

There was a feeling that the document was an excellent vision but there was no guidance on priorities and it would be very difficult to put into action due to lack of funds and resources.

The areas that seemed to show the most challenges was mandatory staff training, information sharing and screening. Again this is due to lack of funding and available qualified staff and incompatible computer systems. There was also a concern that an over reliance on the third sector may occur.

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

The two areas that came through as making the biggest difference was staff training (recommendation 3) and information sharing (recommendation 5). If it was possible to implement these areas this would make the biggest impact on Dumfries & Galloway. However it was also recognised that staff training would need ongoing development and updating to ensure a long lasting approach.

It was also highlighted that an audit should record unmet need so there is a true picture of need and provision in the area.

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

Who is responsible for ensuring that the strategy is taken forward? There was a concern that some staff may feel that they just have to get on with it, putting pressure on staff and services.

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.

Service users:
There was a mixed response from people with sensory loss and carers about the current provision of services. Many were satisfied with what had been provided but there were some with negative personal experiences that they shared.

There was an acknowledgement that funding cuts had negatively affected the services and that staff were under pressure. People were waiting for a home visit and found it difficult to cope during this time, resources were being spent in other areas therefore some services and provision were diminishing.

Technology, aids and equipment can be very expensive and some people felt that this prohibited them buying them. It was difficult to be able to go and try equipment without having to travel to another area for an exhibition.

There were also some concerns raised about care homes and lack of knowledge and understanding amongst staff which negatively impacted on service users. Sensory impairment training for paid carers was highlighted as an area of concern with more people being supported in their own home through Self Directed Support. It was felt that more should be done in this area.

Some people felt that there was lack of continuity at times due to staff changes and not seeing the same person at each appointment.

A better understanding of the challenges of travel to hospital for sensory impaired people should be considered when setting appointments so enough time is given for people to get to the hospital and transportation to other hospitals for procedures was difficult and challenging.

The Hard of Hearing drop in clinics for hearing aid care and maintenance was given as an example of an improvement in service delivery making hearing aid care and maintenance as well as emotional support more accessible to people whilst reducing the pressure on NHS staff.

There was mixed responses to the one stop shop approach although there were some positive comments from people who had accessed a one stop shop for a different reason. Some people felt that visual impairment and hearing impairment should stay separate but be joined up at the point of delivery.

Professionals:
Professionals felt that the services in Dumfries & Galloway were good especially taking into consideration the challenges of geography, staff and resources. They acknowledge that cut backs had had an impact on the service people received and there was one suggestion of looking at current provision to ensure there was no duplication of services.

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

There was a real division of responses to this question. Those that were negative about it felt that it would have little or no impact on them (professionals and services users) as it would not be implemented due to funding restrictions. Some felt there was no point implementing screening without funding the services to meet the increased demand.

The other concerns expressed were around merging hearing and sight loss together and whether this would impact on the specialisms and therefore reduce the service currently being offered.

The majority of people, however, were positive about the strategy saying that it would:

- Improve understanding and therefore the experience of people accessing services
- Improve communication between services
- Reduce duplication of work and resources
- Improve transition from children to adults services
- Improve the experience of people with sensory loss and another health condition
- Support opportunities for people e.g. learning and employment in Dumfries and Galloway.

“Working together is always a better approach”.

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?

The responses to this question were quite polarised. At one end of the spectrum, several stated that little of no knowledge of GIRFEC or the Doran review did not allow them to make any comment whilst at the other there was an understanding of these documents and a variety of opinions on their value.

Some comments welcomed placing individuals at the centre of the planning and endorsed the idea that person centred should also mean child centred. Early intervention especially for children was welcomed as was the notion of a care pathway which covers a life time, providing ongoing support to parents and carers and at key times.

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?

Service users:
Transportation and environmental issues – This is a key for many people with sensory impairment living in Dumfries & Galloway. Transport links need to be better and more accessible to people with sensory loss. The infrastructure needs to be improved to ensure safety of people with sensory impairment. There are too many potholes and uneven surfaces that can lead to significant injury. People become isolated.

Technology – This needs to be more accessible for children, young people and adults. It is a key to independent living and job prospects.

Learning and Employment – More support for learning and employment to ensure an independent future.

Professionals:
The Government needs to take more ownership of the strategy and prioritize nationally. Guidance should then be given to local authority for local implementation.

The framework should connect more with other strategies e.g. Self Directed Support Act and stronger links made.

Funding needs to be allocated to the strategy to allow implementation. Training and screening has a significant impact on staff and resources.

IT interfaces have to work better as systems that cannot communicate make it difficult for staff and ultimately for the service user. All services need to be involved right from the start to ensure a seamless approach.