

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.

From several strategy consultation events held in Edinburgh,

- Respondents indicated that the term “sensory impairment” is a very global one and is not truly reflective or representative of the different cohorts contained within it.
- Each group and sub group within this term has very different needs specific to their visual/hearing and or visual and hearing loss
- Some respondents also indicated that “pathways” could not be a one size fits all approach for sensory impairment
- Services for people with acquired impairments would not necessarily be the same for those with congenital impairment.

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

- People indicated having British Sign Language (BSL) Services available for appointments (particularly health related settings) and not relying on deaf people to make this arrangement by bringing a relative or someone to interpret for them.
- A number of people indicated that written notes were often used as a substitute where English is often not the individual’s first language.
- The lack of availability and choice of interpreters and having to pay and for them on a 2 hourly basis (even if this whole time allocation is not required) was felt to be a key component of supporting services.
- The often lengthy wait for interpreter availability hampered the ability for individuals to plan effectively
- Examples from banking and legal experiences were given to illustrate the extent of discrimination people received as a BSL user.
- Reference was made to the voucher scheme which operates in Nordic countries which allows a personal annual allocation of hours which can be used flexibly as and when required.
- Some suggestions were made for remote video interpreting services which may resolve some but not all of the issues identified. People felt that more websites should have BSL translated links to assist people to access the information and services they require
- Having a central point for hearing and or visual loss where people could go to seek information was welcomed.
- In addition having regular screening for hearing or visual loss in older age was thought to be a helpful recommendation.
- In general, people felt having a register would be useful measure to provide statistical data and were in agreement to sharing information across the sectors, as long as they knew exactly what information was being shared.

- Financial support for assistive equipment- people with visual impairment reported that equipment for them was often more expensive for them compared to other disability equipment e.g. talking software is £1000+ and DLA does not cover this
- Transport- increased number of buses/routes which use recorded speech for destination alerts for people with visual loss.
- More awareness about the impact of street furniture impeding the mobility of people with visual loss
- Need to have system to provide support post diagnosis to contact people at a later date/stages
- Mandatory sensory/deaf training essential for frontline staff and employers to negate grounds of “health & safety” being used as an excuse for not employing individuals with sensory impairments.
- Respondents felt reduced length of time/wait and increased choice for specialist equipment would be beneficial
- If people with BSL needs were not supported effectively, people felt issues of mental health may increase.

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

- System changes to capture more accurate and detailed information
- Process changes to assessment and documentation
- Service analysis/planning with all relevant partners including service users
- Staff training / awareness raising
- Review information provision and access mechanisms to ensure all levels of accessibility
- Review provision across whole pathway , including transition points
- Embed recommendations into relevant strategic plans i.e Prevention , Self Directed Support

(d) How will you make these changes?

- Build on existing good practice
- Working in partnership with specialist providers
- Working in partnership with NHS to undertake joint strategic analysis/planning for current and future service provision and development requirements
- Undertake staff training needs analysis
- Awareness raising of sensory impairment impact
- Work with established sensory projects to target areas of hidden sensory loss such as Learning Disability, Stroke and Dementia
- Ongoing review/ benchmarking of service provision
- Continuous engagement with service users to co produce future service provision which is fit for purpose
- Feedback to the consultation participants and use groups as engagement channels
- Link with Scottish Vision Strategy and other UK strategies

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 felt the key factors in order of importance were

- Mandatory training/screening
- Information sharing
- Care Pathway

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

- Identifying and mapping the specific needs of people with of people with varying sensory impairments.
- People are often all grouped together in systems and processes so it is difficult to extrapolate specific sensory impairment detail.
- Ensuring all staff are trained at all times especially in service areas with high turnover e.g. care assistants
- Not having standards of sensory impairment training makes it difficult to benchmark competency levels
- Not always easy engage with the relevant individuals without being able to easily identify the population in the absence of a register or database.
- Some respondents indicated people gradually adapt to their sensory impairment or accept the service as it is without complaining.
- People are reluctant to complain/identify improvements so sensory services do not change

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

- Employment
- Transport
- Technology
- Integration with Health
- Links with Education for Childrens' Services
- Communication support

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?

- Screening will have additional resources implications for this change of practice- roles and responsibilities will need to be clearly defined
- Mandatory training levels will be more difficult to achieve in areas with high staff turnover.
- Many services are externally provided so maybe difficult to monitor/ enforce this training within private sector e.g. home care
- Pathways will need to be whole system and person centred to be truly effective.
- Ensuring that information is available and accessible to everyone
- Data systems do not support collection or production of condition specific information.
- Personalisation ethos supports/prioritises person not condition based approaches.

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

- Services knowing about each other shared understanding of roles remits and responsibilities will result in improved outcomes in services for users
- Linking sensory impairment to other conditions and not viewing in isolation
- Central point for information
- Linking with other pathways so that people with multiple conditions/needs are addressed effectively and not on a condition based approach
- Making sure all staff are sensitive to the issues connected to sensory loss to increase access and service provision
- Ensuring information does not break down at transition points i.e. from children to adult services and adult services to those for older people
- People also volunteered that having their GP and consultants electronically linked by computer had helped improve their service in recent years

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

- Employment.
- Transport
- Technology
- Integration with Health
- Links with Education for Children's Services
- Emphasis on Reshaping Care for Older people given future demographic projections
- Communication support

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.

Several participants were able to offer a comparative example of NHS Lothian audiology services with those they had received elsewhere including Grampian which provides an excellent drop in service for tubing, having moulds done and return of your hearing aids to your electronic programme. It was felt that the service in Grampian worked around the individual and provide a “one stop shop” model. Complaints were voiced regarding the unhelpful and lack of accessibility to audiology in NHS Lothian including the new telephone system which is difficult to use.

People agreed that it was often luck that they found out about services and entitlements as a deaf or hearing impaired person. “One stop shops” or central points where everyone knew what could be provided at the out set were deemed to be very important way to ensure people were aware of what was available and pathways were seen as a system for potentially achieving this outcome. People also wanted to see more joined up services and not having to go to see lots of different people for related issues. People did not want to be left without hearing aid provision if their own were being repaired.

VSS services at the Eye Pavilion were cited as a good example of linking up services for people with visual impairment to signpost individuals and to help them navigate the maze of services and supports.

One stop shop provision can provide a central hub point for information and treatment. However location and accessibility are crucial considerations to complement locality planning and equity of access for more rural areas.

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

People commented that this is difficult to respond to without experiencing the full implementation of the strategy. Other respondents indicated that another strategy in isolation would not make a difference to their life.

Many people indicated that good communication support would make the biggest difference in their lives.

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?

Some respondents indicated that Getting It Right for Every Child was the over-arching and driving strategic approach irrespective of a child's disability or impairment.

GIRFEC already reinforces the whole system approach for children including those with sensory impairment so another strategy will not have any impact in this area.

Although there are strategic commonalities of priority, including early integrated assessment, single point of access and information sharing.

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?

Some participants expressed their dissatisfaction with the terminology of "pathways" and the technical language used throughout the strategy. They did not feel "journey" was meaningful or personalised to them or their own situation