

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.

Separate responses to be submitted to include views of service users / carers

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

Separate responses to be submitted to include views of service users / carers

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

- NHS pathways are within paediatric and adult audiology and ophthalmic services are well defined and there is a need to continue to support effective transition to allow continuity of care. Work continues to be supported by NHS Lothian's Modernisation Team in both ophthalmology and audiology services to ensure pathways are efficient and effective.
- Further work needs to be undertaken to define pathways out-with hospital settings related to need.
- Unlike visual impairment, there is no register for those with hearing loss, this should be considered at a national level.
- Involvement of health, education and social services in multidisciplinary meetings for those with complex needs
- Promote the use of Self Directed Support as a model of care
- Delivery of pathway changes to deliver the See Hear strategic framework will focus in the work plan of NHS Lothian's Physical and Complex Care Programme Board and this will bring consistency to pathways developed across health and social care.

(d) How will you make these changes?

- Quantify the demand for services given the aging and multi-morbidity population
- Multi disciplinary and multi agency planning

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?

- Development of a integrated health and social care pathway that is clearly understood and outlines referral routes associated with the pathway for a number of professionals (optometrist, GPs, audiologists, ophthalmologists)
- Pathways to include where there is opportunity for early intervention
- The majority of hearing impairments in babies is identified via the Newborn Hearing Screening, there is a need to ensure those identified with hearing impairment at birth are given the opportunity for ongoing assessment of hearing loss.
- Staff training for those involved in sensory impairment services to ensure support in appropriate methods of communication, this should form part of the induction programme
- Register for those with hearing impairment
- Development of One Stop Shop approach where appropriate
- Locality provision of some aspects of the service i.e. hearing aid battery replacement within local areas (to avoid travel to central Edinburgh)
- Continued provision of contracts with the voluntary sector
- Consider telehealth / telecare innovations to support self management

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

- Speech and Language Therapists (SLT) try if they suspect presence of sensory loss through a communication assessment but again not all are trained specifically and not adequate equipment or resources. SLTs can then refer to the audiology department.
- The Sensory Champions would also help to raise awareness with carers, but this and the above examples are not sensitive enough and are not true screening - many people that subsequently fail the audiology assessment have passed these.
- NHS Lothian currently have a pilot project that would be at the required level of sensitivity – a joint SLT and Audiologist screening that has responded to referrals from Community Learning Disability Teams (CLDT) and so far screened one housing provider-plan to screen a day centre for people with complex needs. There is not the capacity to roll this out across Lothian – but need to consider the key learning points and consider how we can deliver equitable and appropriate access across Lothian.

- With the Audiology department the Learning Disability SLT service has developed joint specialist ALD clinics for people who need more time and a different approach, including links with CLDTs via SLTs - however this is not equal across all areas of Lothian. In order to comply with the recommendations NHS Lothian would need to identify resource to enhance capacity and the range of localities offering this service.
- Support electronic transfer of referral information, advice requests and data sharing (secure e-mail / SCI gateway) associated with optometrists, GPs and local authority.
- Promotion of Sensory Resource Centres within the primary care workforce to allow sign posting

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

- The range of need, and personalised access arrangements for these different levels of need should be taken into consideration. This applicable to a number of service user groups for example learning disability
- Ideally –there would be three levels of access. Not everyone can access the Audiology Dept Mainstream provision –a) some People with Learning Disability can and do – b) most need more time and a different approach, but can be seen at the hospital clinic and c) some need a specialist service in their own environment. (This may be due to support issues; complex needs; severe ASD; challenging behaviour; mental health issues e.g. anxiety or in the case of hearing sensitivity need testing in their own environments to assess the environment. At present only level a) is universal across Lothian.
- Review of NHS facilities to ensure appropriate to the needs of those with sensory impairment such as telephone systems, layout of reception / waiting areas

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?

- Currently even if people have been tested, the information is not routinely passed on in the most accessible way to everyone involved. This can result in people not having their sensory needs taken fully into account and repetition of assessments.

NHS Lothian has developed some client accessible resources to address this but it is very time intensive to translate the Audiology notes into this format and it is not routine across all of Lothian. A pilot in West Lothian tries to do this but does not always managed and it is not routinely in place everywhere. The Sensory Champions joint passport is a good format and would go some way to tackling this. A significant challenge is in how we could translate the information from the audiology dept in the form most easily accessible to other professionals, carers and clients; passing it on and ensuring that this is collated centrally.

- Recommendation 1 – Audit
Identifying expenditure for people with sensory loss will require a review of Patient Administration Systems as sensory loss is not routinely flagged in systems and there will be issues in identifying expenditure associated with social care, voluntary organisations and carers. It is also important to consider categories for recording i.e. older people who have visual impairment and wear spectacles, do these individuals need to be identified ?
- Recommendation 2 – Screening
Consider life stage approach to screening, new born, teenage years, further education and older age
- Recommendation 3 – Mandatory Training
There is a need to develop training programmes appropriate to contact with those with sensory impairment to include basic awareness, front line staff in contact with those with sensory impairment and specialist training
- Recommendation 4 – Local Partnerships
There is a need to outline and understand the capacity and demand for the future provision of services
Ensure equity in provision of service across Lothian particularly associated with the voluntary sector
Develop NHS outreach services i.e. hearing aid battery replacement
- Recommendation 5 – Robust Systems to Maintain Local Information
As previously highlighted there is no facility on TRAK to flag individuals with sensory impairment and previous comments have been made relating to sharing of information between agencies and secure referral / advice routes.

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

- Improvement in access and awareness of sensory impairment and ensure individuals feel confident to approach health and social care services for support
- Audit and supporting data collection although the difficulties associated with this have been highlighted
- Potential to introduce life stage screening to minimise impact on individual's lives
- Review of models of care and pathways to drive improvement

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

The paper acknowledges that there is a higher prevalence of hearing impairment in the population of people with a learning disability (PWLD) than in the general population. It would be helpful if it also mentioned that PWLD often have limited or no verbal communication, therefore sensory impairments in this population are frequently unrecognised.

It would be helpful if the paper were to identify the specific hearing support needs of people with Down's syndrome because over 50% of them develop sensorineural hearing impairment (Down's Syndrome Medical Interest Group, 2001).

Many PWLD may have difficulties accessing mainstream services and so, in order to fully benefit they require specialised services designed to meet the specific needs of this population. In addition, specialist materials may be required to communicate the purpose and content of assessments.

They often require access to specialist audiological services because they need longer appointment times and additional appointments to enable successful audiological assessment. The availability of specialist functional visual assessment for people who have profound and multiple learning disabilities such as that provided by RNIB is patchy across Scotland. NHS Lothian are engaged in partnership work with RNIB to jointly fund support workers to assist with visual assessment with people with learning disability than struggle to access mainstream screening / optometry assessment processes.

PWLD who have hearing and/or visual impairments require specialist care pathways.

Information for older people and PWLD should be provided in accessible formats in order to support the effective use and maintenance of hearing aids.

Training and advice for learning disabilities support staff is as relevant as it is for those supporting older people. Health professionals involved across the disciplines require additional training to support PWLD to understand and participate in screening, they may require longer appointments or more appointments to complete aspects of the assessments.

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.

NHS Lothian sensory impairment services are provided in the main at the Lauriston Building for paediatric and adult audiology and the Eye Pavillion for visual impairment services. Specialist in patient services are provided within the Head and Neck Service and Ear, Nose and Throat Department at St. John's Hospital

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

- Ensures needs of those with sensory impairment and delivery of the framework will support action
- Includes staff in pathway redesign and review
- The need to consider capacity and demand as promotion of the strategic framework may increase demand for services

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?

GIFREC ensures that every child is safe, healthy, achieving, nurtured, active, responsible and included. The provision of clear pathways will support families to access support and clarify responsibilities for care. Effective sharing of information will support the GIFREC principles.

The Doran Review highlights every child has the right to become a successful learner, confident individual, effective contributor and responsible citizen, wherever their learning is taking place. Again the provision of clear pathways and opportunities for sensory impairment screening will ensure individuals are not disadvantaged.

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?

It is disappointing that the draft strategy only considers sensory impairment in terms of visual or hearing loss. Hearing sensitivity (Hyperacusis) is often found to be an additional difficulty experienced by people with learning disability, especially those also considered to have challenging behaviour and/or to be on the Autistic Spectrum, but who due to the nature of their difficulties are less likely to be able to report this and seek help through the usual channels. The disorder affects 7-8% of the general adult population and up to 50% of those with autistic spectrum disorder. It would be helpful if the needs of these individuals were recognised within this document.

Similarly the paper does not mention the needs of patients who have tinnitus. About 10% of the UK adult population have tinnitus all the time and in about 1% it may affect their quality of life. Both hyperacusis and tinnitus may be linked to challenging behaviour in PWLD.

Challenging behaviour exhibited by children, young people and adults may well be reduced or more appropriately managed by the individual and their cares by increasing opportunities for environmental interaction and identifying barriers to communication such as hearing and visual impairment.