CONSULTATION QUESTIONS

1. The strategy outlines a care pathway (page 10).

1(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.

Feedback from users of services in East Lothian commented:

The care pathway will support integrated approaches to the provision of health and social care, including hospitals, GPs, care homes, local Vision Support Services. It will also help with issues experienced by older people with dementia and hearing loss by linking services for older people and sensory impairment services.

In relation to 'one stop shops', it was thought that a single point of contact was a good idea, but in a rural area it would need to be virtual and multi-agency, with all members of staff having understanding of sensory impairment.

Staff commented:

Highly commendable. This will help to establish a holistic approach to sensory impairment and overcome the current situation of 'silos'. An older person with dementia and a sensory impairment, for example, currently will not experience an integrated service. Rather they will need to repeat information to the different services and deal with a range of different staff.

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

People using services commented:

Culture change
Awareness raising needs to lead to significant culture change in relation to everyday respect for and understanding of sensory loss within our communities:

- "Most people don't treat you with respect or dignity. It's a cultural thing. People find it very difficult to deal with people who have difficulties".
- "I've had verbal abuse from people who did not take kindly to my guide dog being taken into a cemetery…I tried to explain to him and I was so angry at the way I spoken to. Why does no one understand sight loss?"
- "People think that I can't be blind because I don't look it".
- "It would be good to challenge some of our councillors to go through a day in the life of…".

Time and place: Consider the needs of working people:
'Today at this meeting, the timing is not great. I spoke to people in East Lothian and they were working. Some have replied but they are busy. Perhaps after working hours more people could come. You might get different perspectives and services and people talking about loops and all sorts'.

Provide communication support
Any communication support needs to be good quality and provided in a consistent manner so that people can rely on it being available when needed. Particular mention has been made of the lack of resources and understanding for people attending health services. This lack has an evidenced impact on both physical and emotional health and needs to become a priority to be addressed.

Provide emotional support
Staff commented that there seems to be more of a focus on offering emotional support to individuals and families, rather than just referring on. This development was welcomed. People with sight loss identified two types of support that are necessary – mobility and emotional support.

Staff commented on the importance of **raising awareness:**
Ensuring staff and the local community understand the impact of sensory impairment is vital. This should include practical sessions on dealing, for example, with memory loss and sensory impairment through promoting positive practice. This would include looking at alternative methods of communication and understanding how to assist someone to access alternatives. It would also include information on the administration of medication. A person with sight loss may need more than a prompt to take their medication. Some care at home contracts do not allow for this.

A key point about sensory awareness training is that, if the person moves to a new job, they take that understanding of sensory impairment with them to their new role.

Both staff and service users commented that training needs to be refreshed and updated regularly.

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

At a Lothian level: - In partnership with the Lothian Joint Physical and Complex Care Programme Board a working group should be established to determine the current partnership arrangements, support the audit and initiate discussions around the development of the care pathway. The pathway needs to be designed with Self Directed Support principles in mind. Existing arrangements should be reviewed and mapped. Some issues:

- Consistency needs to be applied across the country and within Lothian. Similar practices need to be observed by all authorities or service users or this could present a problem for health staff working across several authorities.
- Consideration will need to be given to registration of those with hearing loss. It will be important that the deaf community leads this discussion of the benefits and disadvantages for those affected.
- Explore the use of technology to support service delivery – eg the implementation of the DALLAS/LivingitUp in Lothian platform to support sharing of information, provide signposting to support, and enhance peer support for users.

At a local level:

- Develop a programme of awareness raising training and an expectation that all staff will participate
- Develop single points of contact: in rural areas these need to be virtual and multi-agency, with all members of staff having a good understanding of the impact of sensory impairment
- Increase numbers of staff trained locally in sensory rehabilitation in view of the high numbers of people who have visual and hearing loss
- Improve our standards of sensory impairment assessment to a level that enables decisions to be made on approval for services
- Explore the provision of and assess the need for more locally accessible specialist services, including specialist day opportunities for young people with sensory impairment and complex need
- Integrate the provision of specialist equipment for sensory impairment with the provision of tetelecare/telehealthcare, in view of the fast pace of change in relation to sensory impairment technology and the improved availability of equipment.

1(d) How will you make these changes?

East Lothian's Physical Disability Joint Planning Group will lead on implementing the changes arising from SeeHear. Audit Scotland advises that there is a need to plan and deliver outcomes[1]: the care pathway needs to translate into delivery, with partners working together to implement both Lothian and local priority outcomes. As part of the pathway design, there must be a clear understanding of the respective contributions from partners, and how overall resources will be targeted to deliver the priorities. This will require service integration, a focus on prevention, and investment in the people who deliver services. The demand for services in the future needs to be quantified.

East and Midlothian Councils are currently working with RNIB and Deaf Action to review our contracts with them and to develop a shared sensory impairment service. We will use the information gathered from the consultation process to further inform our discussions about developing services and support. We also hope to develop a local reference group for sensory impairment.

Service users who participated in the consultation have an expectation of feedback on the process – this is essential and will be a good base to start the dialogue on the Care Pathway design.

2 (a) The strategy identifies key factors that need to be in place to ensure that the pathway is successful (page 11, para 6.7). Which of the key factors are most important for a successful pathway?

People who use services chose these factors:

Maintaining information

In particular, understanding prevalence was seen as a key priority.

Awareness raising training was considered to be the top priority, as it is key to bringing about the change in culture identified as necessary to improve the expericne of people with sensory impairment and their families:

- "You would expect at hospital that people understand sight loss…the doctors/consultants, but at the Eye clinics they often don't".

Screening

Services need to be committed to basic screening - early intervention is often key. The liaison between GP/Council/NHS needs to be good. Families are impacted by screening – there needs to be intervention for families **and** individuals and established links between screening and interventions.

2 (b) Which of the key factors are most challenging to put in place?

People who use services chose these factors:

[1] Audit Scotland 2013

Sharing information consistently

Consistency of approach

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

Communication support was identified as the key factor that needs a higher profile within the Strategy document. See also 3b

People who use services also chose these factors:

- The transition of children through the various education stages and then onto work afterwards.
- Support for children who perhaps do not wish to use hearing aids and be identified as different.
- Support for those who wish to attend college, many dropped out of university/college courses finding it too difficult to continue studies.
- Transport was a key barrier for people with sight loss and not included in this framework

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?

Recommendation 3 - Mandatory training

- People who use services in particular feel that this is vitally important
- The use of equipment to give people a "blind" perspective should be used as this gives real insight to the difficulties experienced.

The DALLAS/LivingitUp platform could be used to access the different levels of training as well as organisational learning and development facilities:

- Basic awareness – introduction and understanding
- Front line staff dealing with sensory impairment
- Specialist training.

Training was perceived as fundamental for:

- All staff/professionals in health and social work
- Families and carers
- All authority staff including customer service desks, libraries, council tax, transport
- In hospitals, GP surgeries, care homes
- Transport operators
- Schools should start awareness training – to stop prejudice against deaf and blind people – introduce guide dogs and the difficulties walking with a white stick. Let them try an obstacle course without being able to see
- Chemists, transport, banks etc.

Recommendation 5 – Data collection

People who use services commented that there is a reluctance around information sharing because of data protection regulations.

- "Individual permission has to be asked. You may not want some things known to some services as you feel there will be a different response,

whereas other services knowing is ok. That is an individual choice".

It was felt that this is an important issue to resolve because while people wish to retain control over their personal information, they also have the experience of going to different departments and being asked the same questions all the time, which is time-consuming and unnecessary.

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

"A combination of all of them".

Recommendation 1 – Audit

- It was generally felt that it would be a good idea – however thought it would be difficult to identify all hidden costs:
  "Recommendation 1 is around an audit of service spend, where it is currently spent, but there are gaps between what is spent and what people need. Will the audit pick up on that?"

Recommendation 4 - Promoting effective local service provision

People who use services felt that this would make a considerable difference, and suggested some improvements that would help:

- Ability to phone in at a certain time to guarantee someone at the end of the phone – answer phones are no use to people with sensory impairment
- More extensive use of text messaging eg to make appointments
- Consulting local user groups with ideas of improvement
- Raising awareness of staff of the support available and enablinging them to pass this information on appropriately

Recommendation 6 - Compliance with the Equality Act 2010

People using services commented:

- " We need to be highlighting good areas and share (this) across the Council"
- "The document talks about sharing good practise etc, but we don't currently do that now"
- "You've outlined people with sight loss are more likely to be on low income or unemployed…a good example – I can't drive to the tip, but I am expected to pay the up-lift fees, or for talking books".
- Need to improve accessibility - "How difficult is it for the council to provide information in a format which people understand?".

Staff thought equality training is particularly necessary for staff in statutory agencies. Understanding of Equalities is often confined to the designated Equalities lead officer, and best practice is not embedded across council and health service systems. An example of lack of awareness is Library Services fining people with sight loss for overdue library books. A person who is using large print books will not be able to read the print information on library fines, which is in standard size print.

Add Communication support/ Environmental issues /Transport as key focuses under Recommendation 6 Compliance with Equalities Act

Communication support

Interpreting services on their own are not always the answer, people need the correct training to use interpreting services effectively and the quality of interpreting needs to be good:

- "I had a big problem; I was looking for work .... I did not know the interpreter and the signing was poor. The person was not using BSL, it appeared that they just used someone who could use a little sign language, I had to refer to notes and I was not happy. I wrote a letter of complaint. In the past deaf people had been with this same interpreter before and no one had complained. If someone does not speak English they get a spoken language interpreter and it is important for deaf people to get the same equal access".

Services users asked why the British Sign Language Act has not had more impact in terms of improving services for people with hearing loss.

- "I think BSL should be in there..... I have a deaf family; I am the 5th generation in our family. We have all had the same problems with access; the barriers are still the same".

Environmental issues

Key environmental issues include:

- **Bin collections**
  - "Even if it became a habit that the bin men put [the bin] on one side or in a specific place so you know how to avoid them"
- **Shop sandwich board signs on the pavement**
  - "There are local things (shop signs in the street) which are obstacles – some can be dealt with, some are not so easy. If you are using a guiding cane then you have mobility problems – a guide dog makes it easier"
- **Road crossings**
  - "Dunbar High Street ..... is unsafe to cross – the crossings are there, but they are all unsafe. A man had to actually get out of his car and stand in the middle of the road to stop traffic so that I could cross safely".

Transport

Many comments about transport were made, with all in agreement that it is a missed area in the Strategy. Issues included the need for public transport to stop at bus stops or to provide audio services. LRT, Edinburgh and Glasgow buses were all said to be good, as were Scotrail services. More locally, Perrymans and Prentice buses were praised for their attention to people with sensory impairment.

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

Wellbeing

Staff commented:
Transition arrangements for young people leaving school should be highlighted in the Strategy, both in terms of improving wellbeing and ensuring good access to post-school opportunities

People with hearing loss and deaf people who use BSL experience greater difficulties in accessing health services and receive a lower standard of healthcare across the board[2]. Needs of BSL users should be paramount in this framework.

A brief dialogue between a person who uses services and a member of staff about the impact on wellbeing of waiting for an interpreter:

- "Say a deaf person is older, in a care home and they are the only deaf person there, maybe their mind goes a little quicker due to lack of stimulation. Perhaps they have sore legs or something. They may have dementia too and may not be able to explain thoroughly to the doctor. Hearing people can be more direct; for a deaf person they may not be able to communicate their problem. For blood transfusions and for people with cancer there has been late diagnosis because of waiting for an interpreter". " That is interesting, the government [has] said that deaf people's health is worse and maybe this is linked. Maybe you should get an interpreter anyway as a small thing may turn into a bigger thing".

Prevention

There should be more preventative services at point of diagnosis ie spend to save. We should focus on interventions with younger people, as the earlier we intervene, the more effective it is. We need to change the culture that professionals know more about sight loss than people using services, they may not. The approach needs to be more consistent. People using services would like to have professional advice, but will ask for it when it is needed.

Emotional support

Staff commented that there seems to be more of a focus on offering emotional support to individuals and families, rather than just referring on. This development was welcomed. People with sight loss identified two types of support that are necessary – mobility and emotional support.

Recognition of sensory impairment as a long-term condition

Sensory Impairment is a long term condition and should be recognised as such – and promoted on the DALLAS/ LivingitUp platform.

Uses of technology

People with hearing loss are keen to use new ways to help them book appointments or to contact staff across a range of agencies. These include faxing, texting personal mobiles, emailing and accessing online interpreting services. Extending the use of technology in this way could be explored by the DALLAS /LivingitUp platform.

[2] Deafness, Cognition and Language Research Centre, 2012

The provision of specialist equipment needs to be integrated with the provision of tetelecare/telehealthcare, in view of the fast pace of change in relation to sensory impairment technology and the improved availability of equipment.

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.

Current provision of Services by East Lothian includes the following specialist and generic services:

Ref	Service	Details
a.	Deaf Action	• Provision of specialist services to meet the needs of deaf people. • Contracted by East Lothian Council to provide social work assessment, specialist equipment and communication support.
b.	Royal National Institute for the Blind Scotland	• Provision of specialist services to meet the needs of people who are blind or partially sighted • Contracted by East Lothian Council to provide rehabilitation and mobility service, social work assessment, registration and certification, core equipment items.
c.	Carers of East Lothian	Carers of East Lothian provide information & support service to unpaid carers of all ages throughout East Lothian. Services provided to carers include: • Quarterly Newsletters, emotional support, signposting and referral to appropriate support services, carer support groups, training for carers.
d.	East Lothian Young Carers	East Lothian Young Carers provide information & support service to young carers throughout East Lothian.
e.	North Berwick Lip Reading Group	North Berwick-based Lip-reading group for people who have hearing difficulties.
f.	East Lothian Community Care Forum	ELCCF gives people a platform to voice their views and ideas on how best community care services run by health boards and local authorities can be planned and delivered. Organises feedback through Community Action Research projects.
g.	EARS Advocacy Service	Independent advocacy for older people, free and confidential.
h.	Occupational Therapy and Technology Services – Telecare and Telehealth	• Ensures personal and property safety through provision of Telecare / Assistive Technology. • Provides a range of technology to promote safety and independence in the community. Staff assess, train, review for telecare equipment • Assessment for specialist equipment can be progressed by Occupational Therapy.
i.	East Lothian Library - Outreach Services	A Library service provision for those people who are housebound due to frailty, illness or disability.
j.	East Lothian Access Panel	Advises East Lothian Council on design and redesign of resources and processes.

Service users in East Lothian made the following comments:

Libraries

- "People are unaware of what is there – I do use the library and have had some really good experiences. Audio books are widely available and downloadable"
- "I love my daisy books, but you don't get the same selection through the library – the library in Dunbar is limited. It has been improved but it 's not my first choice of where to go for books"
- "I have no knowledge of any other services…I don't know what I can use or what I am entitled to"

Information

- "How do you find out I'm there? And how do I find out about services? I found out about the Blue Badge, but had to go through RNIB to find out about it"
- "I'm not known by the Local Authority or what services I can access in my Local Authority, I only know people that I see walking around. The strategy talks about joined up services in Health Board, statutory and third sector – and training/services needs. It doesn't currently exist at all…well done to this document for suggesting it"
- "People don't know what exists"
- "Services are going to be patchy, but that's due to limitations put on budget. There's a funding allocation problem"
- ".....[People with] sensory impairment ....are not a generic group – we don't need a generic social worker. We do need a specialist worker".

Transport

- "A lot of services would be fine if they were done properly i.e. people park in a bus stop so the bus driver can't see you and passes by".
- "Bus routes? Talking buses?"

GPs and hospitals

- "The doctors, when you are in the waiting room just shout. Sometimes you have to lip read the receptionist. It would be great to have a screen where your name comes up"
- "The sensory service, I think it is the same all over the UK - not good. If I have a problem and go to the doctor they may not know how to book an interpreter. They say we can go through a few notes but I do not understand"
- "One of my deaf friends broke his leg playing football. He was taken into A&E and wrote a note saying he was deaf. A nurse came out and was talking to him, I wasn't sure if it

was my friend they were talking about. It was written down that he was deaf on the sheet but the hospital did not arrange anything"

- "They know I am deaf but at the hospital they do not know. I am looking about, they are asking for ..[me]... and I am looking around not knowing! I say I am waiting for my interpreter".

  Staff commented that Doctors' surgeries should be designed with people with sensory impairment in mind – calling out names is not suitable for those hard of hearing and waiting rooms should be designed better for blind people.

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

As per previous sections

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?

Staff commented:

- GIRFEC provides the framework for those who work with children and young people, including those with sensory impairment, their families and carers. Effective sharing of information within and between agencies is fundamental to improving the lives of of children and young people, especially those with sensory impairment
- See Hear needs to foster an **integrated approach to training**. This means initiating integrated training pathways to enable practitioners to develop skills which can applied across a variety of settings
- Teachers, pupil support workers should all be given basic training and more specialist training if there are children with sensory impairment in their class
- A further concern is children who choose not to use hearing aids.

People who use services commented on the **poor provision of information** when children are confirmed as having a sensory loss. Information is passed on, for example about cochlear implants, but nothing about RNID or Action on Hearing Loss, which is essential for deaf people

The Strategy requires additional focus on **transition issues** for young people: Staff commented:

- "When children leave school they may be cut off. Deaf children may not know where to go for a hearing aid check. If they have always gone to audiology for checks they may not know that they can get other equipment as well."

- "Some children when they leave school do not realise that if they miss an appointment they go to the bottom of the list. We are trying to put in a transition period so they have a priority appointment so they can get their hearing aids upgraded if possible. Also we are trying to have e clinic day so their hearing aids can be checked before they leave the service so they ..... leave our service with the best possible equipment. Some young people do find it difficult when they can no longer go to paediatrics".

- "Transition is the big thing for us and ensuring that colleges and universities have transition afternoons. We ....have work groups with the adults and the children separate so there are different questions.....some do reject the system and it is making them aware that what they do not want in high school they may find effective in college, notetakers and access to interpreters, lip readers etc - explaining all of this. We are doing this Lothian wide....We have spoken to colleges and they have offered something on paper but the child attends and the notetaker is not there. We see children drop out because they do not have the support".

A service user commented on his experience of transition to college:

- "I went through this myself at college. I did a business management course ..... I asked for an interpreter and notetaker. They did not know how to

contact. They said it was too expensive. I went through a year of trying to get something set up and it was a constant battle. In the end I pulled out of the course. You expect things to be there in college. My girlfriend had the same experience and that was 10 years later. This has to be worked on".

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?

Comments on the See Hear document

- Needs a contents page
- The key statement on p2 should be in bold:
  'People who develop a sensory loss need to understand what this loss will mean for them, and must be able to access information and be supported to take the maximum possible control over how they are able to live as independently as possible, while also getting direct assistance when they need it, including in communication with others'.

- Needs to be in user friendly language and in plain English:
  "The consultation needs to be in 'normal' or accessible language so that we can understand what's afoot and feed in properly"

- At 5.4, add National Dementia Strategy: Promoting Excellence, Knowledge and Skills Framework for Dementia Care. This has implications for the workforce development element of the SI Strategy.

- How is this Strategy linked to the Public Protection agenda?

- Appendix 1: Funding should be made available for recommendations 3 **and** 4 as the development of local care pathways depends on the skills and awareness of the staff involved.

Comments on the local consultation process

Focus groups were held in Musselburgh in East Lothian during the daytime. Groups were facilitated and participants were supported by Deaf Action and RNIB. Individual members of staff were also consulted.