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 provided in West Lothian commented as follows:

- Rigorously set pathways were regarded as a good idea by all the focus groups
- Users would like to see pathways – written up clearly and suitable in a range of formats as appropriate to the sensory impaired
- Service users are bewildered by the number of people involved from the different agencies and would like to see a more integrated approach
- A single point of contact is most important – to know where to find people, indentify most important issues

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

Feedback from users of services provided in West Lothian commented as follows:

- Medical and social work staff are urged to **please look at people** – apart from being a common courtesy it is vital for people who lip read to understand information being imparted. This should form part of communications training for all staff not just training for deaf awareness. "It is obviously not part of current medical training!"
- GP's appointments need to be planned better – they are difficult for those with sensory impairment. Doctors shout out names at time of appointment – those hard of hearing cannot pick this up.
- Rather than the current "conveyor belt approach" greater responsibility should be on clinical staff to provide information for users at the point of diagnosis. The emotional wellbeing of the individual should also be considered, one lady was told by a nurse "we don't do that".
- Everyone needs some time to understand their condition and the opportunity or platform to come back with questions. "A contact point would be good" – someone who knows the issues and understands problems faced by people who are hard of hearing
- Users don't necessarily want more professional support, people who have experience of the condition are much more value. Staff just have to "care" not necessary to go the extra mile
- A network of support arrangements needs to be established; facilitating this really important. Many users are aware that information and help is available, but trying to access this when emotionally upset is really difficult. This should include the range of services provided by the voluntary sector
- Do clinical staff undertake user evaluation exercises? If not how do they know they are getting it right?
- One service user advised that her child, who also had a hearing problem, was told he had "failed" his hearing test – this left the impression that somehow blame was attached to the problem and took considerable time and effort on her part to persuade her son otherwise.
- Hard of hearing users were also told that they were "pressing the test button just for the sake of it" by a member of staff
- *One service users advised that she was told she was deaf by a GP's and advised to "get on with it", another was told to "eat green vegetables" no information was provided in support.*

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

- Until the pathway is designed it is difficult to do so? Where would the single point of access be – health or social work?
- This will require cultural change and systemic innovation– in accordance with Nesta report "New systems often fail when they demand everything should be changed all at the same time. Almost without exception successful new systems cleverly incorporate elements of the old systems to make them easier to use, more familiar and to minimise learning"[1] - Clever systems innovators know when to clothe the new in the old, to incorporate older elements into new systems to make them less threatening.
- At a Lothian level - In partnership with the Lothian Joint Physical and Complex Care Programme Board a "task force or sub group" should be established to determine the current partnership arrangements and support the audit. Existing arrangements should be reviewed and mapped. Does this need to be a full time role for a short period?
- Setting out to change this complete system is ambitious needs to avoid falling into the trap of tinkering at the edges and changing part but leaving the rest untouched. The right people need to map the pathway and the development of the provision, they need to commit to it and ensure that it is sustainable. All partners and stakeholders need to be involved, including GP's, opticians, ophthalmologists, optometrists, independent optometry consultants, social workers, audiologists, eye clinic development staff, voluntary sector, and more especially carers and service users. A means of communicating with each provider is fundamental to the success of the pathways
- Registration will be fundamental to the redesign – already exists for those with sight loss and needs to be created for those with hearing loss.
- Consistency needs to be applied across the country and in the Lothian area. 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.
- Explore the use of technology to support service delivery – can the use of mobile networks be expanded to deliver advice and information to users e.g. the implementation of the DALLAS/LivingitUp platform should support sharing of information and provide signposts to facilities and support available. It should also galvanise peer support for users.
- At a local level:
  - West Lothian Sensory Support Service is one means of providing a focus for disseminating information, similar groups could be set up in other authorities
  - West Lothian's Model Office Project should help integrate systems to ease the referral and assessment process and the smooth transfer of data.
- Need to retain the ability for home visiting opticians service which is highly regarded
- Outcomes and means of evaluation needs to be determined
- The pathway needs to be designed with Self Directed Support principles in mind.

[1] NESTA, 2013

1(d) How will you make these changes?

- By systemic innovation i.e. an interconnected set of innovations, where each influences the other, with innovation both in the parts of the system and in the ways they interconnect. [2]
- In accordance with advice from Audit Scotland there is a need to plan and deliver outcomes[3]: 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.
- We need to consider the use of options appraisal to ensure that the services provided are effective and demonstrate best value. Has best practice been identified elsewhere?
- Adapting and reforming existing systems will be difficult, and the involvement and commitment of clinical staff and GP's in the process are vital.
- Complaints from service users about treatment in shops, banks, buses etc., suggests a need to involve the business community perhaps by strengthening partnership arrangements with the Chambers of Commerce? This may also provide an opportunity to secure and source apprenticeships or gain support for the transition of young adults with sensory impairment into work placements.
- When mapping the existing relationships and current pathways feedback should be sought from those involved in the process especially front-line staff that usually has good ideas to build on.
- 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.
- An overall communication strategy should be introduced to inform all concerned of progress – this should be in plain English and in all available formats. There needs to be consistency in disseminating information from the consultation and for the implementation of future strategies.
- The cultural implications need to be addressed and thought through and the needs of ethnic minority groups must be taken into account
- Provision of information in the new pathways will not be a one-off exercise and will need constant review and revision.
- Training is essential for front line staff and also senior clinical/specialists. Resources need to be made available to overcome the resistance from staff for training where time and funding are both an issue for release.

[2] Nesta 2013

[3] Audit Scotland 2013

2. The strategy identifies key factors that need to be in place to ensure the pathway is successful (Page 11 para 6.7).

2(a) Which of the key factors are most important for a successful pathway?

Key factor that needs to be in place to ensure pathway successful - - as per framework	2 (a) Which of the key factors are most important for a successful pathway?	2 (b) Which are the most challenging to put in place?
Factor 1 It is important that referral routes into support services are clear to those undertaking diagnoses, and that information is available in appropriate formats to the individuals themselves. For the majority of people, the point of diagnosis will be undertaken primarily through NHS Audiologists, ophthalmologists, optometrists or independent optometry practitioners. Others will first become engaged through their GP	• It is important that all potential entry points are mapped onto the pathway and that consistency is applied no matter which point of entry is used. • The referral process should be as smooth as possible.	• Multiple entry points will prove a cultural challenge. It will require that staff to have a background knowledge of the framework, an awareness of the pathway and perhaps more importantly a willingness to support it. • Ensuring that awareness of the pathway is maintained and sustainable will be the problem as staff change. A comprehensive training programme will need to be introduced perhaps based on using the DALLAS/LivingitUp platform as the communication channel. This should also be part of induction training.

Key factor that needs to be in place to ensure pathway successful - - as per framework	2 (a) Which of the key factors are most important for a successful pathway?	2 (b) Which are the most challenging to put in place?
Factor 2 It remains a cause for some concern that there is no standard set of expectations in relation to maintaining information in relation to people with the various diagnoses of sensory impairment. Such information is basic to understanding the prevalence of impairment and then being able to monitor the reach of services, engage with service users and carers, identify and learn from best practice, and identify gaps and opportunities for service improvement;	• Data sharing between all involved is fundamental to the success of the pathway. • There is a pan-Lothian agreement for a shared assessment tool. • West Lothian has a single shared assessment which provides detailed information about the service user, and is currently looking at a more integrated assessment of need.	• Streamlining of referral and assessment process should be a top priority • From an authority perspective acquiring consent to share data from service users is a major problem and ways to streamline this issue need to be investigated. • Service users did not regard this as a major issue (providing there was an option to opt out) and felt that this would make life easier for them if this information was shared particularly e.g. when interpreters are needed to support medical appointments or that staff should be aware that they have a hearing problem and may miss important information.

Key factor that needs to be in place to ensure pathway successful - - as per framework	2 (a) Which of the key factors are most important for a successful pathway?	2 (b) Which are the most challenging to put in place?
Factor 3 A commitment to the consideration of sensory impairment being included in generic assessments, and development of integrated service provision that actively promotes opportunities for assessment and service provision across both the different types of sensory loss and also the agencies involved: in some areas, this could build on recent One Stop Services activity. Agencies and disciplines should have robust, coordinated arrangements for information sharing and a commitment to local care pathways to best meet the needs of local service users. They should be aware of the opportunities offered by their distinct legal and practice frameworks, and to take advantage of any such opportunities to provide person centred solutions for individuals;	• Service users felt that the assessment of those with sensory loss is a specialist skill and this should **not** be compromised. • All focus groups did not think that data protection issues were a problem if a need to opt out of registration etc., was offered. They were keen that ways information can be shared was considered. • Recording of sensory impairment was welcomed for patients in hospital where some dreadful experiences were highlighted particularly in cases of hearing loss. • Recording that an interpreter is required was regarded as essential in case notes • Registration for both hard of hearing and visually impaired is vital for the pathway to be implemented.	• Streamlining of referral and assessment process should be a top priority • Users will be happy not to have to explain their circumstances every time they encounter professional support, irrespective of the agency. • DeafAction already have access to SWIFT/eCare • Unless registered, we are unaware of potential users – how to we engage them?

Key factor that needs to be in place to ensure pathway successful - - as per framework	2 (a) Which of the key factors are most important for a successful pathway?	2 (b) Which are the most challenging to put in place?
Factor 4 A commitment to maximise basic screening for sensory impairment, which can readily be undertaken by non specialist staff, with onward referral where there is an indication of sensory loss. This could be done at GP surgeries when the person reaches an agreed age, or at key times of engagement, e.g. assessment for other community care services or admission to a care home;	• All focus groups agreed that this was an excellent idea and felt it should be part of the pathway. • Provision should be provided at a range of stages – particularly at schools. • Provision should be in accordance with existing arrangements for Bowl and Breast Cancer screening – perhaps a one stop shop to do all?	• Resources would need to be dedicated to undertake the screening and whilst appearing expensive at the outset a cost benefit analysis should be undertaken with the costs of **not** screening. • Identifying the hidden costs of not screening should be considered in conjunction with the "Choose Life" consultation • Depression and other affective disorders were the 5th most common group of conditions reported in GP consultations in 2009/10[4]. During the focus groups a number of service users commented on experiencing depression and some even advised that they had considered suicide due to the isolation experienced with hearing loss. More research is required to determine the connection between sensory impairment, depression and dementia and the associated cost implications.
Factor 5 A commitment to a single point of access wherever possible, including for ongoing contact. This places a responsibility on services and agencies to work together effectively and reduce duplication and confusion for the individual;	• Service users felt that a one-stop shop model would be really useful but felt that there were still areas that needed to be more connected, e.g. hospitals • Authorities have good working relationships with the voluntary sector with contracts in place with RNIB and DeafAction to provide services. • Service users have urged that the referral process should be easier	• West Lothian currently has the Sensory Resource Centre which provides a service to users in the area. The profile of this facility needs to be raised in particular amongst those in primary care.

[4] Scottish Government Statistics 2012

Key factor that needs to be in place to ensure pathway successful - - as per framework	2 (a) Which of the key factors are most important for a successful pathway?	2 (b) Which are the most challenging to put in place?
Factor 6 A clearly developed set of local sensory impairment care pathways that are agreed by key stakeholders and understood by all clinicians,	• Service users confirmed that they want to see seamless pathways from their perspective and a clearly developed set of local pathways that are agreed by key stakeholders and understood by all clinicians **and GP's** with the roles within the pathway need to be defined • They want more focus on giving information – signposting • Accessibility is really important, different sections not sure how this would look – interpreting facilities need to be included	• Links between agencies providing support need to be strengthened.
Factor 7 A commitment from statutory agencies to seek to agree the maximum possible consistency of approach across Scotland, and ensure similar access to services across Scotland;	• Note the consequences of increased awareness will lead to an increased demand and additional strain on resources.	• To standardise approaches pan-Lothian they should be coordinated under the auspices of the Lothian Joint Physical and Complex Care Programme Board • "Overall groups felt that if those who should have an understanding of the individuals experiencing sensory loss/lack communication/don't work in an integrated manner and cannot even get the basics right - then what hope is there for the wider society."
Factor 8 A commitment to awareness raising training for front line staff that may have to deal with people with sensory impairments.	• All focus groups agreed unanimously that awareness training was fundamental to the development of the pathway. • Particular comment was made that training was not only required for front line staff but more importantly for GP's and clinicians – note the comment about "looking at people" in Section 1.	• Training can be set up but resources need to be provided • Those on the front line should be involved in the process of designing the pathways – they are much more aware and generally have very good ideas. • Those working with people with sensory impairment should be asked – what would

Key factor that needs to be in place to ensure pathway successful - - as per framework	2 (a) Which of the key factors are most important for a successful pathway?	2 (b) Which are the most challenging to put in place?
		make a difference for you to be able to help someone?

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

- One of the key factors in ensuring success of the framework is to break down barriers between organisations and many stakeholders felt that changing existing organisational cultures was a necessary prerequisite to achieving this.
- Some of the barriers presented will be managing conflicting priorities and the need to produce a range of different plans, funding bids and policy documents is perceived by many stakeholders to be both an unnecessary burden and a distraction from developing service provision further.
- Many of the key partners involved in Sensory Impairment have had to deal with and are still dealing with major organisational change. This in itself is unsettling and is perceived as having made it much more difficult to develop effective partnership working
- Other areas highlighted by focus groups of particular concern are
    - 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. (One former teacher commented that she knew those children in her class with a nut allergy but not those who had a sensory impairment)
    - 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
    - Staff training needs to be comprehensive, appropriate to the role performed and expanded to include all areas
- In some areas, lip reading classes have to be paid for, users commented that if physiotherapy is free – why not lip reading? It forms part of rehabilitation and education and takes up to a year to be proficient, but it does build confidence.
- Service users also commented that they were aware that Audiology Departments needed to achieve targets and the "production line" approach to delivery was not person-centred, and left with many questions unanswered.
- The consequence of increased awareness will be increased demand, how will services gear up to this?
- Layout of facilities is important:
    - New people attending audiology find it very confusing – they have to bypass normal reception – no warm feeling
    - "Waiting room at St John's was changed to a row of chairs – particularly difficult for wheelchair users"
    - Users are scared to move in case their name is called when they move away.
- Raising awareness amongst the general public is essential, sensory impairment is hidden and needs elevated. Feedback suggested that the Equality Act 2010 had not made a difference; in fact many users advised that organisations are unaware how to use loop systems.
- The effects of deafness in particular are not understood by the general public and raising awareness is key e.g.
    - Hearing aids do not match hearing loss and
    - Lip reading doesn't entirely match either – there is an element of guess work and the concentration required is immense,
    - The importance of lighting and acoustics not appreciated
    - To make appointments you need to phone which so often triggers the answer phone, these are universally disliked by all service users
    - Alternative arrangements need to be made for those with sensory impairment e.g. – fixed time for calling?

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?

Feedback from users and staff on all the recommendations is summarised as follows:

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 – how is the cost of depression attributed to sensory loss shown in an Audit?
- Who would undertake the Audit – should this be in partnership with the Lothian Joint Physical and Complex Care Programme Board?
- It was felt that spend however would not necessarily equal effectiveness and how could this be measured?
- The Integrated Resource Finance Data (IRF) information needs to be made available to undertake this research as well as information from primary care.
- Identification and classification of those with sensory impairment needs to be considered and structured to ensure data in the future.

Recommendation 2 - Screening

- One note of caution was to ensure that screening was undertaken by those appropriately trained. One example was highlighted of an older person being diagnosed with dementia when all they were suffering from was tinnitus.
- Screening perceived as vital by every focus group consulted and they felt it national checkups when age stages are reached i.e. statistics show hearing deteriorates for the >60's (75%) should they be screened regularly, in the same way for bowel screening and mammograms. It was felt that screening would slow up the deterioration process and people were looked after better once "in the system". Whilst the cost may be prohibitive to introduce a cost benefit analysis may perhaps show the potential savings of this preventative exercise.
- Users advised about the screening test done over the phone by "Action on Hearing Loss"
- It was suggested that screening could perhaps be included in things like "Well women clinics" i.e. – "A one stop shop" for wellbeing was thought to be a good idea as prevention strategy
- Testing for hearing not necessarily regarded as "preventative" spend however the consequences - what is the cost of "not" screening? What is the cost of someone with depression?
- DeafAction's counselling service was regarded very highly and this type of facility is really needed by deaf people.
- Note that checkups in soundproof rooms are not really representative of the outside world and whilst people may be happy with their hearing aids in this room – they find it really different outside.
- Ways of notifying users of appointments needs to reflect their condition.

Recommendation 3 - Mandatory training

- Every focus group agreed that this was "absolutely essential" and need not be difficult to implement
- Three levels of training were identified and it was thought that use of the DALLAS/LivingitUp platform could be used to access this 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 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 – staff in Audiology will advise that "it's over there" to people who are blind and seeking information
- Job centres, tax offices
- Teachers, pupil support workers should all be given basic training and more specialist training if children with sensory impairment in their class
- 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 4 - Promoting effective local service provision

- To ensure that local provision reflects the local circumstances, the future demand for services needs to be carefully mapped and consideration taken of Scottish Index of Multiple Deprivation [5]information. How do we reach those not yet in the system?
- More and more users are accessing the Web for information. The facilities available for users in West Lothian need to be collated and highlighted in one source which should have a programme of sustainability incorporated. It is hoped that this can be achieved using the DALLAS/LivingitUp platform. These facilities need to be in appropriate formats to suit those with sensory impairment. Papers and instructions need to be provided in Plain English – people who have been deaf all their lives use English as a second language and may have a learning difficulty "*the old deaf people amongst us need to understand what is being said – plain English please?"* People, who are deaf, sometimes have a limited range of English – and information needs to be straightforward and jargon free.
- Transport for users presents a problem in accessing local services in West Lothian. Part of the plan needs to determine the extent of this.
- Could "live chats" be introduced for those unable to use telephones? Answering machines are universally hated by those with sensory impairment.
- RNIB has a really good shop in Edinburgh but this is inaccessible to people in West Lothian – could a local provision be arranged – fixed times of the month?
- The Sensory Resource Centre has extremely good links with the partners and this should be developed further.

Recommendation 5 - Registration

- RNIB currently register those with a visual impairment and they would provide information to help determine the cost of introducing a similar register for those with hearing impairment.
- All focus groups agreed that registration for all sensory impaired was an excellent idea and the advantages of being on a register outweighed the disadvantaged. It was stressed that there should be an opportunity to opt out if desirable. Those with hearing impairment would like the advantages and disadvantages of registration outlined by those already registered.
- Registration would provided the evidence to champion for better facilities and opportunities
- There are benefits of Registration for the visually impaired, e.g. Blue Badges, VAT reductions these benefits need to be outlined for those with hearing impairment
- How deaf would you need to be to register, mild, profound – where would you draw the line?

[5] Scottish Government, 2012

Recommendation 6 - Compliance with the Equality Act 2010

- All focus groups considered this to be vitally important however the enforcement costs could be considerable. It is difficult to understand how service users can still face discrimination with such legislation in place, however people with a sensory impairment lack confidence and often don't exert their rights
- It was felt that the introduction of the Equality Act – has had little impact since there is no regulation on loop systems. All groups felt that equality training is vital – theory side – legal rights need to be enforced; practical side – what makes a difference – a toolkit for help!
- Problems experienced with loop systems are as follows:
    - Installing Loop systems has been perceived as a tick box exercise in most cases
    - Loops are set up in organisations but staff are unaware how to activate
    - In some cases batteries have been taken away for use elsewhere.
    - Supermarkets have systems but they don't work
    - When taxis are serviced they need to prove that they can accommodate a wheelchair but no-one services the loop system
    - When advising an organisation that their loop system wasn't working a user was told that it would be her hearing aids that were wrong
    - Public buildings should have loops built in - if providing wheelchair access – why no accommodation for hearing loss?
    - Fire alarms are tested in shops – why not loop systems?
    - Implementation not regulated or inspected
- The rights of users need to be highlighted and those with sensory impairment should challenge organisations more, they need to know how to make complaint against services or individual staff
- Signage was regarded as one of the biggest difficulties for sensory impaired Information and notices are usually too small to read – particularly if staying overnight in hospital – e.g. shower instructions were dangerous and "Care homes are particularly bad"
- Food labelling a real issue
- New buildings
    - Are up and operational before asking about the installation of hearing loops – acoustics are usually really bad
    - Are open plan with no doors which are really difficult for sufferers of hearing loss – too much background noise especially if no carpet

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

Recommendation 1 - Audit

- The Audit is important and needs to consider money costs and resources however will be difficult to determine hidden costs and may not make a difference to service users.
- Identifying the total funding available was perceived as important since major service delivery changes cannot be made without appropriate resources

Recommendation 2 - Screening

- Screening at a variety of stages would make an impact, particularly in the case of children when transferring stages
- Staff felt that screening would help identify those not picked up "by the system" and could prevent further deterioration in conditions

Recommendation 3- Mandatory training

- Users in particular feel that this is vitally important, not only for front line users but from people serving the public in all walks of life.
- The use of equipment to give people a "blind" perspective should be used – as per RNIB – this gives real insight to the difficulty
    - Why is there not a proper resource centre here? – this issue has been raised for the past 4/5 years

Recommendation 4 - Promoting effective local service provision

- Users 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
    - Specialist phones at Help lines or Eye Clinic – sign showing direction is insufficient for those with visual impairment
    - Use of "live chats" or more extensive use of text messaging is important
    - Consulting local user groups with ideas of improvement
    - Raising awareness of staff of the support available and allowing them to pass this information on appropriately
    - St John's OPD – would be helpful if able to forward information, where situated does not suit those with visual impairment. The electric lighting is very poor.
    - Doctors' surgeries – calling out names is not suitable for those hard of hearing, waiting rooms could be designed better for blind people –they come across obstacles such as pillars and men sitting with feet out in waiting rooms. Blind people cannot see until up against things and the potential for falls is considerable.
    - There was a competition to see how many times users had visited the wrong toilets – signage on toilet doors is a particular hazard.
    - "Computer literacy – those who are in their 50/60's who develop sight loss, will be computer literate, but access to equipment and information about change is very difficult to come by.

Question: Why don't we have a one-stop shop here? – this was perceived as being the most important to service users

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

As per previous sections
Other issues identified:

- Part of the strategy is to maximise self-management and to support people live with the conditions they have – more support needs to be provided to facilitate this.
- We need to quantify the demand for services in the future.
- There is a responsibility with the sensory impaired themselves to get involved, taking part in the consultation is empowering.
- Sensory Impairment is a long term conditions and should be recognised as such – promoted on DALLAS/ LivingitUp platform.
- Children need supported to become fully independent adults in all social aspects – ensure that enough support regarding rehabilitation using GLOW – low numbers make this difficult and culturally a challenge

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.

4.1 Current provision of services by West Lothian:

Ref	Service	Details
a.	Sensory Resource Centre	• Offers specialist social work advice and services for people who are deaf, blind, hard of hearing, blind, partially sighted or deafblind • Provides advice on mobility and equipment to improve safety quality of life and independence • Support and counselling to individuals affected by sensory loss • Spends time in own homes to assess needs • Provides equipment to aid daily living • Gives support and advice to carers and relatives • Facilitates the Sensory Support Service Meetings, which happen once a month in the Sensory Resource Centre and are attended by voluntary organisations commissioned to provide support by West Lothian.
b.	Deaf Action	Deaf-led registered charity established in 1835, offices in Edinburgh, West Lothian and Highland • Provision of specialist services to meet the needs of deaf * people (training, communication, support services, social work, information and advice). • Contracted to West Lothian Council to provide social work, specialist equipment and care at home / housing support for deaf people.
c.	Royal National Institute for the Blind Scotland	West Lothian commissions RNIB to provide the following services for people who are blind or partially sighted: • Rehabilitation and mobility service This service offers 1:1 support and training from a trained Rehabilitation and Mobility Officer based on specialist assessments of needs and outcomes-focused care and support plans • Core equipment items A core list of items designed to assist blind and partially sighted people will be provided to those people assessed as requiring them
d.	Carers of West Lothian	Carers of West Lothian provide information & support service to unpaid carers of all ages throughout West Lothian. It is the only organisation having a specific remit to support unpaid carers. **Services provided to carers:** • Carers Information Pack (containing information on local services and support available to carers) • Quarterly Newsletter (keeping carers informed of local and national initiatives to support carers) • One to one emotional support • Home visits • Signposting and referral to appropriate support services • Access to advocacy • Access to counselling • Carer support groups • Training courses for carers • Recreational courses (such as holistic therapy and basic massage) • Individual support for young carers (between 10 and 16 years) • Group support for young carers
e.	Vision Support West Lothian	Support group for the blind and partially sighted in West Lothian. Voluntary group who attend the Sensory Support Service.

Ref	Service	Details
f.	Lip reading classes	Organised by Work with Adults and Communities Team , lip-reading classes for people who have hearing difficulties
g.	Minority Ethnic Health Inclusion Project	• Provides a service for minority ethnic individuals and communities Lothian-wide. • Provide a multi-lingual link worker advocacy service • Tackle health inequalities through health promotion/health improvement
h.	Mood project	MOOD identifies older people 55+ who live in West Lothian and are at risk of or are diagnosed as having a depressive illness. The group offers a range of resources to help prevent premature admissions to institutional care.
i.	Disability West Lothian	Disability West Lothian was established in 1976 and founded as a Company with Charitable status in 1988. It comprises of individuals and representatives of organisations who work for and with people with disabilities who are committed to improving the quality of life of disabled people in West Lothian. Disability West Lothian provides the following Services: • Disability West Lothian • Disability Information and Advice Service • Learning Disability Information and Research • West Lothian Access Committee • Living Book Project • Partnership Initiatives • West Lothian Peer Counselling Service A team of staff and volunteers are committed to delivering high quality services. Services are for people with disabilities, their families and carers; service providers and policy makers; and the general public in West Lothian
j.	Deaf & Hard of Hearing Support Group	The group aims to socialise, support and advice about equipment, information on deaf / hard of hearing issues, contacts and links to other organisations
k.	EARS Advocacy Service	Independent advocacy for older people, free and confidential
l.	Occupational therapy and technology services – Council Home Safety Service	• To ensure personal and property safety through provision of Telecare / Assistive Technology. • The Service provides a 24-hour a day telephone link between the equipment installed in the client's home and the West Lothian Careline, ensuring the client has access to help when and if it is required. • The Home Safety Service provides a range of technology to promote safety and independence in the community. Staff assess, train, review for telecare equipment and provide a response to emergencies for those service users without key-holders. • Assessment for specialist equipment can be progressed by Occupational Therapy
m.	Intowork West Lothian	Intowork West Lothian is a specialised employment and support service working within West Lothian. • The service works with people aged 16 – 65 who have an acquired brain injury (either as a result of accident or illness) helping them to find and sustain employment • Support is provided on a one-to-one basis throughout the job finding process and includes: • Assessment of needs, interests and abilities • Vocational and recruitment guidance • Work placements and work trials • Support in the workplace • Advice and guidance for employers
n.	West Lothian Library - Outreach Services	A Library service provision for those people who are housebound due to frailty, illness or disability.

4.2 Service users in West Lothian made the following comments:

- Future services need to give old and young deaf people a positive experience
- Networking is poor – no "care Pathway" and will be hit and miss depending where you get into the system.
- **Appointments with GP's and specialists**:
    - Have a limited time and it is difficult to go through all the information needed during that period.
    - They are concerned with passing on the technical information and are reluctant to take into account emotional wellbeing/quality of life and ultimately confidence
    - To make appointment s you need to phone which so often triggers the answer phone – alternative arrangements need to be made – fixed time for calling? Answer phones are despised by the hard of hearing
    - It is sometimes unsuitable for members of the family to accompany users to medical appointments – BSL support is really necessary there are not enough interpreters or funding for interpreters
    - Can visual scroll displays be introduced so that people can see things if hearing is an issue?
    - Fine once you get into the system – 3 months to wait after diagnosis with very little support.
    - Notes on the wall of Audiology Dept cannot be read by visually impaired
    - When diagnosis is delivered it is crucial that you are signposted for support – some people were told over the phone and the shock was considerable. Some were told not to drive with immediate effect – how do they get back from the hospital? One lady was told to go away and eat plenty of spinach!
    - One-stop shop at St John's – booth available but location poor – not widely advertised or known about
    - "The business of joining up service and one stop shops clearly needs to be addressed in even the most basic manner"
    - "At the point of diagnosis, more responsibility needs to be taken. When you are told, everyone needs to understand their own condition. There was no department or individual, no information given – even though I was perfectly capable of receiving it. It's about how people are and should be dealt with as individuals"
- **Equipment:**
    - Would the one-stop shop provide better information and support regarding equipment? Would this include options of equipment for those with multiple conditions – e.g. front door safety? A solutions catalogue would be useful – to see what equipment is available and how it could improve your life.
    - When first issued with hearing aids the user gets a 10 minute guide how to use it – this is not adequate and some users do not fully utilise the aid, basic instructions and support needs to be improved. At the time of issue users should be directed to organisations such as DeafAction, Lip Reading Classes and Sensory Support Service.
- **Workplace:**
    - Job Centre – giving out order numbers is a waste of time for someone who is deaf
    - People mentioned going to the Job Centre and getting nowhere – or being sent for jobs which are completely inappropriate – call centre for a deaf person?
    - Not all deaf people have a good command of English (2nd language). It is hard to digest some things written down particularly if in "office speak".
    - How do people in workplace have meaningful appraisals if they cannot communicate with their line manager?
    - Access to services is difficult for people who work – important that you feed that back into the consultation
- **Children**
    - People with sensory impairment commented that they did not get much support at school
    - Takes a long time for other children to accept their condition
    - More support needed in the classroom for deaf children
    - Review meetings for children have too many adults round the table – can be daunting for a

child
    - Transition to college needs support and proper resources
    - High incidence of leavers amongst deaf students - no funding for interpreters etc.
    - Some debate ensued about a college for Deaf People – advantages and disadvantages discussed
- **Perceptions:**
    - Deaf people feel less equal to “normal people” and “Attitudes to deaf people suck”

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

Staff comments:

- Staff in West Lothian felt that the framework would not be effective unless contributed to and supported at all levels.
- It was recognised and welcomed as a major cultural change however concern that insufficient resources would be allocated to the change process would prevent complete service redesign.
- Front line staff were anxious to be included in the design process and urged that carers and service users form part of the design team.
- The implications of Self-direct Support need to be considered
- If awareness is raised – how will staff cope with increased demand for services?
- Are the timescales to implement strategy – a protracted ambition –could we run pilots early on and look for quick wins and opportunities, perhaps funded by Scottish Government?
- Could we run a similar scheme to highlight "Sensory Aware" organisations
- Can we review "Apps" currently available and how they can help with the daily lives of service users – e.g. The Scotrail App was a great benefit to a lady with visual impairment who regularly travels by train.

Service users commented as follows:

- The specific services need to be defined, roles identified and how they fit into the overall framework explained.
- Different routes need to be outlined for the different needs i.e. Visual loss and hearing loss need to be kept separate and the importance of each recognised.
- Special consideration should be given to those managing – self support – but have a specific problem, it may too difficult to access mainstream services
- Dementia sufferers are supported for 12 month period following diagnosis – can those with sensory impairment be guaranteed a level of support post diagnosis?
- RNIB and DeafAction provide excellent support – prevention of social isolation makes a difference to people's lives
- Communication supports and needs should have more focus
- Recognition of obligation needs to be highlighted
- Certificates of training could be issued – to show deaf awareness amongst staff
- Means of providing support in rural areas a priority
- 36 week waiting list for hearing aids is unacceptable

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?

- West Lothian firmly believes that effective sharing of information within and between agencies is fundamental to improving the protection of children and young people.
- GIRFEC provides a consistent way for people to work with all children and young people and forms the bedrock for all children's services. It is also used by practitioners in adult services who work with parents or carers. The approach helps practitioners focus on what makes a positive difference for children and young people – and how they can act to deliver these improvements. Getting it Right for Every Child, nationally and locally, is being threaded through all existing policy, practice, strategy and legislation affecting children, young people and their families.
- The Getting it Right approach includes a Named Person for every child, from birth (or sometimes before), until they reach 18.
- One plan is produced for each child, to be used by a single agency or several agencies working together to support the child and to mace sure the child is supported through key transition points. This ensures a careful and planned transfer of responsibility
- This applies to all children and young people including those with sensory impairment.
- Under this system, an easily accessible summary of information will be compiled that allows further dialogue and exploration with the child, family and practitioners to help everyone develop a better understanding of the child's well-being and decide what might help. Those involved with the child should have access to specialist support at various stages of the pathway and this will reflect the complexity of the child's needs and circumstances and ensure the implementation of a single agency plan.

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?

- **General:**
  - It would be interested to discover the criteria to determine the funding for Foundation Stage of the strategy. It is also not clear to officers how the Consolidation stage can be resource neutral and the council would seek agreement with Scottish Government that they will fund the full cost of implementation for this and the Integration stage.
  - 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[6]. Needs of BSL users should be paramount in this framework.
  - Recommendations in the Joining Up, an Action on Hearing Loss and Deafness Cognition and Language report should be included in the framework.
  - The implications of Self-direct Support need to be considered
  - Consider the impact of Health & Social Care Integration Agenda on the access to and delivery of services.
- **Wellbeing:**
  - The impact of people being isolated and stuck at home, any other considerations?
  - Life strategies to help people face going out into public
  - Links to dementia need to be explored – how do you help people with dementia know how their hearing aid works?
  - Lip reading classes look after the emotional life as well.
  - Most people regard disability as people in a wheelchair – they are not aware of disabilities of those sensory impaired
  - General feelings of the focus groups were things had to be desperate before they felt listened to.
- **Environment**
  - The provision of good lighting is essential for those with visual impairment, the issue needs to be addressed with social landlords and care homes.
  - The quality of sound in public places
  - Quality of services provided – difficultly in hearing, more emphasis should be placed on the quality of loop systems in public places
  - Shops – signage to toilets and exits is inappropriate
  - Bus stops – notices are usually too small to be read, would be much better being horizontal rather than vertical
  - Transport links and access to transport needs to be considered.

Comments on the consultation process:

- West Lothian consultation exercise undertaken in accordance with the National Standards for Community Engagement.
- A number of users commented that the document would have been easier to respond to if the questions had referred directly to the recommendations.
- A BSL interpreter could not translate the questions for her service users – the language was "NHS Speak" and not plain English.
- Many sensory impaired use English as a second language and found the language difficult; indeed many of the staff did likewise.

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

- Comments from a service user “The framework focus is too much on staff. Is there a register of professionals and a quality framework in place”?