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.

I hope to be able to request the placement on all my NHS files the information that I have a severe hearing loss, automatically flagging up my communication needs (I lipread). I would like receptionists, nurses, GPs, consultants to see this information as soon as I appear for a consultation.

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

Currently it is considered against a person's rights to so label them as having a hearing loss, and this is not recorded in my hospital files as far as I or consulting staff are aware.
I consider hearing loss to be a medical fact, a key feature which requires consideration for successful communication and wish that information to be prominently displayed.

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

(d) How will you make these changes?

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?

'*no set standard of expectations in relation to maintaining information.....*'
Diagnoses of sensory impairment and prescription of spectacles/hearing aid seem to be 'stand alone'events unless the loss is profound and personal/social care is required. Those with even severe hearing loss are considered to be physically independent but their long term social and communication needs are not catered for. My experience with a severe hearing loss is that a great deal of support is needed to manage that hearing loss and to achieve a satisfactory level of communication skills and that there is definitely a breakdown in the pathway after receiving hearing aids. In my area there is excellent support in the voluntary sector but it is not signposted by GPs nor often enough by NHS Audiologists. However, this is improving.

'A commitment to maximise basic screening...'

As many many people do suffer from hearing loss but deny the fact both to themselves and to others, basic screening built in at key stages or health check clinics would be overcome these issues -
At present neither carers, practice nurses, community nurses nor GPs seem empowered to pick up/discuss this problem if dealing with another issue.
An automatic check would circumvent the necessity of self referral and increase early diagnosis and early treatment thus avoiding a lot of distress.
I also feel that as more and more people with hearing loss experience the benefits of support the concept of impairment/hearing loss/aid wearing would lose its fear/stigma.

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

'Service improvement'
'awareness training for front line staff (and human resources staff)...'

for those with hearing loss (where my experiences lie)

I find many hearing impaired fail to successfully adapt to using hearing aids, fail to get optimal use from them, are unable to access lip reading or communication support classes.
Screening, diagnoses, prescription will not be effective unless follow-up support is available and signposted. To many hearing aid users are left to struggle; fail to cope in using their aids; feel let down and unsupported and so give up. This trend must be reversed for hearing loss to lose it's disabling impact.
Those in work fail to get the support they need to continue to work as effectively as they would like as neither they nor their employers know what support is needed/appropriate.

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

People with tinnitus often have hearing loss, or vice versa.
Tinnitus will impact on the deaf person's ability to communicate. There is no cure, only strategies to cope. I don't feel this condition is recognised by generic health care providers. Any care provider who is not deaf aware nor 'deaf empathic'will have no understanding of the issues this condition creates for their client.

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?

Basic sensory screening is a mammoth undertaking with a huge amount of work by front-line staff – nurses, carers, teachers, etc., but of great benefit to those with hidden impairment.

Promoting effective local service provision.
A huge task to bring all services together tactfully and effectively, but would create a pathway permeating the service users'whole life/lifestyle/healthcare provision.

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

Barriers to everyday life
Compliance with the Equality Act 2010 with respect to sensory impairment, and consideration of future action would greatly enhance everyday life for those with sensory impairment and fully include them in society

- working loop systems where ever those with hearing loss (hearing aid users) quire oral discussion/interview.
- The access to/provision of full digital communication, texting, emails etc for ose unable to follow speech on a phone
- a strategy to roll out sensory impairment awareness throughout society.

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

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.

I wear digital hearing aids prescribed by NHS Audiology, they are programmed to my specific needs and the technical service has been excellent.

I have needed support to come to terms with my severe hearing loss and strategies to cope in work, at home and socially. I have also some moderate tinnitus. Those issues have been acknowledged but not addressed.

I have had support from a local hearing support charity which has taught lipreading and given support in many areas of communication. I have regained my confidence, my self-esteem and am much more assertive.

Whilst in employment I found neither my employer (a local authority!) nor I knew what support to put in place for me; I was asked if I would consider early retirement! Audiology had also made the same suggestion. DWP Access to Work programme gave excellent, if limited, support enabling me to continue as an effective employee.

I am now a volunteer running drop-in centres to support other hearing aid users. I am constantly meeting examples of people who have been through the 'system'but are not able to utilise their aids effectively nor cope with communication issues.
I hope the One-Stop-Shop concept will work at community level and include follow-up sessions for the hearing impaired and their families struggling to communicate.

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

I hope that as and when I access health service provision that communication is achieved with ease and without misunderstandings.
I have experienced excellent care and much consideration for my communication needs, most providers have been motivated to give optimum support.
I do, however, often need to be assertive and identify my hearing impairment at the start of each consultation with each new health worker! However, a few are still not deaf aware or fail/refuse to appreciate my specific needs and so cause distress.

I hope I no longer need fear this attitude, nor avoid making health appointments.

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?

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?