

# All Party Parliamentary Group on Deafness

## Meeting | 21 March 2016

Room 21, Palace of Westminster

### Agenda

1. Apologies
2. Minutes of 25 January meeting
  - a. Letter to the Secretary of State for Health
  - b. Letter to the Minister for the Cabinet Office
3. The sexual and reproductive health needs of the deaf community
4. Any other business

## **Minutes of 25 January meeting**

Committee Room 21, Palace of Westminster

### **Present**

- Jim Fitzpatrick MP (chair)
- Lilian Greenwood MP
- Baroness Randerson
- Lord Rennard

### **Apologies**

- Debbie Abrahams MP
- Kate Green MP
- Tommy Sheppard MP
- Lord Shipley

### **In attendance**

- Molly Berry, Association of Teachers of Lipreading to Adults
- Jim Edwards, Chair, UK Council on Deafness
- Robert Geaney, Senior Public Affairs Officer, Action on Hearing Loss
- Ross Matthewman, Parliamentary Manager, Sense
- Dan Sumners, Senior policy adviser, Signature (minutes)
- Roger Wicks, Director of Policy & Campaigns, Action on Hearing Loss

### **Minutes of 7 December 2016 meeting**

1. No Members commented on the minutes when they were circulated. They were accepted as an accurate record of the meeting.

### **Minutes of 16 December 2016 meeting**

2. No Members commented on the minutes when they were circulated. They were accepted as an accurate record of the meeting.

### **Update on the Action Plan on Hearing Loss**

3. NHS England had formed an action plan oversight group. Commissioning was the first issue it was working on.
4. The oversight group formed a commissioning advisory group made up of Clinical Commissioning Groups, Commissioning Support Units, NHS England, Public Health England, Monitor, and the Hearing Loss and Deafness Alliance.
5. The Alliance was central to the discussion at the first meeting. The advisory group largely adopted the Alliance's commissioning principles and accepted the mild-moderate-severe categorisation of hearing loss was unhelpful.
6. Two subgroups, adult services and child services, would draft commissioning guidance. The guidance would be reviewed and approved by the advisory group. Any changes made by the advisory group would need to be approved by the relevant subgroup.
7. The subgroups would meet for the first time on 9 February.

### **Adult hearing screening**

8. The National Screening Committee (NSC) had not recommended an adult hearing screening programme. It would not review the decision for four years.
9. The NSC said the evidence was too limited to establish the type of screening test to be used, the severity of hearing loss to target, the age of the population to be screened, and the frequency of screening. It also said the effectiveness of the long term use of hearing aids and of additional interventions aimed at improving the duration of hearing aid use was also uncertain. It said a randomised control trial was needed.
10. The decision was unfortunate. It seemed the NSC had focused on anecdotes about hearing aids being left in drawers, rather than the evidence about improved outcomes.
11. The NSC decision contradicted the recognition of the action plan that hearing loss was an enormous personal, social and economic impact, and more needed to be done on prevention, early diagnosis and support for those who had permanent hearing loss.

The challenge was too great to wait the five or so years it would take to conduct a randomised control trial of screening.

12. The chair would write to the Secretary of State for Health to request a between him or the relevant Minister and the officers of the Group to discuss how to make sure hearing loss was identified and treated as early as possible. Members would also seek to ask Parliamentary Questions about the NSC decision.

### **Update on hearing aids**

13. All CCGs had paused their consultations about reducing access to hearing aids pending publication of the commissioning guidance. However, North Staffordshire was going ahead with its cuts and the risk of further rationing remained.
14. It was important people were giving good information about access to hearing aids. For example, private businesses which had Any Qualified Provider status should mention NHS aids when marketing private digital aids.
15. The chair would email all Members asking them to submit an application for a Westminster Hall debate about deafness and hearing loss. In particular, the cuts to hearing aid provision that have been made or proposed, progress against the action plan, and the NSC decision.
16. The chair would discuss a potential public health campaign with the Secretary of State or health Ministers. Amongst other things, it would aim to inform people about hearing aid provision and encourage them to have their hearing assessed.
17. Members would seek to ask Parliamentary Questions about the information AQPs must provide to people in their marketing.

### **Lipreading classes**

18. The [Association of Teachers of Lipreading to Adults](#) (ATLA) asked the APPG on Deafness to support their efforts to increase and raise awareness of 'lipreading and managing hearing loss' classes.
19. Molly Belly made a presentation (Appendix 1). She asked for the support of the APPG to secure funding for lipreading classes.

20. Lipreading classes would be included in the briefings for a Westminster Hall debate about deafness and hearing loss. Members would also seek to ask Parliamentary Questions about lipreading classes.

### **Adult education**

21. Jim Edwards, chair of the UK Council on Deafness and chief executive of Signature, explained there was a need to focus on adult education with respect to deafness because

- a. the number of deaf people according to their ability still lagged behind their hearing peers; and
- b. the number of people taking qualifications in communication with deaf people was falling.

22. The devolution of adult skills policy had its merits, but it meant skills which were of national importance might not be identified as a local priority.

23. Adult education would be included in the briefings for a Westminster Hall debate about deafness and hearing loss. Members would also seek to ask Parliamentary Questions about adult education with respect to deafness.

### **Next meeting**

24. The next meeting would be in February/March. Dan Sumners would contact Members.

### **Actions**

1. Chair to write to the Secretary of State for Health, requesting a meeting to discuss the NSC decision, hearing aid provision, lipreading classes and a public health campaign.
2. Members to submit applications for a Westminster Hall debate about hearing loss and deafness.
3. Members to ask Parliamentary Questions about
  - a. the NSC decision;
  - b. AQP providers;
  - c. lipreading classes; and
  - d. adult education.

## **Matters arising | Letter to the Secretary of State for Health**

I am writing in my capacity as chair of the APPG on Deafness to request a meeting with you or the appropriate Minister to discuss recent developments relating to health provision for people who are deaf or have a hearing loss.

We understand NHS England and others are making progress on the Action Plan on Hearing Loss, particularly with respect to guidance on commissioning of audiology services. We are also pleased to note most CCGs have halted their plans to ration the provision of hearing aids pending publication of that guidance.

The APPG remains concerned that North Staffordshire CCG has limited access to hearing aids, and others may consider doing the same. We were also disappointed that the National Screening Committee decided not to recommend a systematic population screening programme of hearing loss in older adults.

Whilst we understand the reasons given by the NSC regarding the need for better evidence about the method of screening, we feel a screening programme would itself contribute to that evidence. For example, when the Newborn Hearing Screening Programme was introduced there was no agreement on the best approach.

The action plan has stated hearing loss has an enormous personal, social and economic impact, and more needs to be done on prevention, early diagnosis and support for those who have permanent hearing loss. The challenge is too great to wait the five or so years it would take to conduct a randomised control trial of screening.

The officers of the APPG – Neil Carmichael, Ian Mearns, Lord Shipley and myself - will therefore appreciate a meeting to discuss how we can make sure hearing loss is identified and treated as early as possible. In particular, we are seeking your support for a public health campaign to encourage people to talk to their GP.

## **Matters arising | Letter to the Minister for the Cabinet Office**

I am writing in my capacity as chair of the APPG on Deafness to request a meeting with you to discuss how the government can facilitate and promote the use of BSL in the course of its work and that of public services.

This follows the meeting of the APPG on 7 December, at which Terry Riley and David Buxton of the British Deaf Association spoke about recognition of BSL. As you will know, there is a growing focus on sign language in the UK, with the advent of the BSL (Scotland) Act and the announcement by the Northern Ireland Executive that it intends to bring forward legislation with respect to BSL and Irish Sign Language (ISL).

We are encouraged by recent steps that have increased access for BSL users, such as the NHS England accessible information strategy and the Department for Work and Pensions trial of video relay access to customer services. A firm foundation is growing on which to base further work to make sure BSL users have the opportunity to make equal progress in education and employment.

I will therefore appreciate a meeting to discuss the possibility of setting up a BSL working group. Its aim would be to consider current access for BSL users and identify some key actions to increase it.

## **The sexual and reproductive health needs of the deaf community**

This briefing note has been prepared by

- the [British Pregnancy Advisory Service](#) (bpas), a not-for-profit provider of reproductive healthcare and education;
- [Deafax](#), a charity which works to empower D/deaf people through specialist training, education and resources; and
- [Deaf Nest](#), an organisation founded by midwife Pauline E. Sporek that works with healthcare professionals to address D/deaf couples' needs throughout pregnancy and childbirth.

### **Overview**

Deaf people need and deserve access to the same healthcare support and services as all other members of society. Unfortunately, this is simply not happening.

Young D/deaf people do not receive the information at school they need to lead happy, healthy relationships, putting this group at risk. Deaf people have told us they face significant barriers to accessing healthcare services, and national data shows that the D/deaf community experiences higher rates of unplanned pregnancy and STIs than the rest of the population.

Many D/deaf women and their partners feel isolated, scared, and unsupported during pregnancy and childbirth. Without a concerted focus on these issues, D/deaf people will continue to lack the support and information they need to look after their own sexual and reproductive health.

### **Sex and relationships education**

Sex and relationships education (SRE) provides young people with essential information to prepare them for the challenges and responsibilities of adult life

There are nearly 38,000 Deaf children in England and over 80% attend mainstream schools. A significant minority (17%) of the young D/deaf people surveyed by bpas and Deafax did not receive SRE lessons in school.

Of those who did receive SRE, the majority missed out on essential information, including topics that are included in the national curriculum:

- 40% were not taught about pregnancy
- Nearly half (46%) were not taught about STIs
- Over one-third (34%) were not taught about puberty

Research has found young D/deaf people are particularly vulnerable to sexual abuse. Yet the majority of those we surveyed were not taught about sexual relationships and the law, and less than half in one specialist school knew the legal age of consent.

Young D/deaf people have a poor understanding of sexual health issues, contraception, and where to go for advice. Issues identified as particularly problematic for young D/deaf people:

- Delivery – inaccessible written materials. No visual communication.
- Communication support – either not provided during SRE lessons or a lack of time during the lessons to explain the information.

### **Access to sexual and reproductive healthcare services**

Young D/deaf people lack knowledge about where to go for sexual health advice, and where their nearest sexual health service is. As a result, many rely on the internet to provide them with essential healthcare information.

Only half of those surveyed by bpas and Deafax felt comfortable seeking medical advice from a clinic. Barriers to accessing support at clinics include worries about communicating with medical staff, difficulties understanding written information, and poor provision of communication professionals at appointments.

Of those women surveyed who had previously had an abortion, almost one third said no communication professional was provided during the appointments and as a result they did not understand the information provided.

### **Maternity care: The Deaf Nest Project**

At a time of when maternity services in the NHS are aspiring to deliver safe high quality maternity care for all women, the challenges of delivering equitable care to women who

have are deaf r have a hearing loss is a challenge that needs to be overcome. By improving communication and developing more inclusive services for deaf and pregnant women, as highlighted in the Deaf Nest project, women and their families will be empowered and more confident in accessing midwives and health care professionals. This will in turn result in women having a positive birth experience as well as healthier and better outcomes.

### *Key findings*

- Antenatal and postnatal services frequently fail to meet the communication, linguistic and cultural needs of deaf mothers and fathers.
- Deaf mothers receive less information regarding pregnancy and parenting issues. There are no accessible resources about pregnancy and parenting. Parents have been left frightened by limited information, no communication provision and a general lack of understanding about the culture of Deaf people.
- Deaf parents have less social interaction with other mothers, which can put them at a higher risk of postnatal depression.
- There is a lack of comprehensive data, which impacts on service planning.
- There is little literature available on providing maternity care to deaf parents. There is an acute need to train maternity health professionals in deaf awareness and associated communication skills.
- The availability of an interpreter, particularly during labour, varies between and within regions.
- Other issues include fear and anxiety of being judged by health professionals regarding caring for a baby skills.

Childbirth can be an empowering and embracing life experience for a woman and her family. Deaf women need to be accepted and supported in their choice to become parents and to be cared for and treated like every other woman.

D/deaf women are disadvantaged in terms of access to the information and care they need, from understanding how to protect themselves from STIs to knowing where to turn if they have a concern or question about their pregnancy. This will have a significant impact on this group of women's health, wellbeing and safety. We urge the APPG to examine these issues and press the government to ensure all women are empowered and able to look after their reproductive and sexual health.