

All Party Parliamentary Group on Deafness

Meeting | 23 May 2016

Wilson Room, Portcullis House

Agenda

1. Apologies
2. Minutes of 21 March meeting
3. Review of progress
4. Any other business

Minutes of 21 March meeting

Committee Room 21, Palace of Westminster

Present

- Jim Fitzpatrick MP (chair)
- Baroness Howe

Apologies

- Baroness Randerson
- Kate Green MP
- Lilian Greenwood MP
- Teresa Pearce MP
- Lord Shipley

In attendance

- Molly Berry, Association of Teachers of Lipreading to Adults
- Lidia Best, Chair, National Association of Deafened People
- Jim Edwards, Chair, UK Council on Deafness
- Sonia Fleming, NHS England
- Beccy Farrow, Campaigns Officer, National Deaf Children's Society
- Charlie Podschies, NHS England
- Gillian Rollason, Social Policy Manager, Action on Hearing Loss
- Dan Sumners, Senior policy adviser, Signature (minutes)
- Roger Wicks, Director of Policy & Campaigns, Action on Hearing Loss

Minutes of 25 January 2016 meeting

1. No Members commented on the minutes when they were circulated. The Group accepted them as an accurate record of the meeting.
2. The chair and vice chairs would meet with the Minister of State for Community and Social Care on 27 April to discuss early identification and treatment of deafness and hearing loss.

3. The chair wrote to the Minister for the Cabinet Office to discuss the possibility of setting up a BSL working group. The Minister had not yet replied.
4. The secretariat contacted the office of Mark Griffin MSP regarding Scottish MPs visiting the APPG to brief Members on their experience of the BSL (Scotland) Act. The office had not yet replied.
5. The Group had not yet been successful in securing a Westminster Hall debate on hearing loss and deafness. The chair encouraged Members to keep submitting applications.
6. Work to implement the action plan on hearing loss was progressing well. The oversight group met recently. Work on the commissioning framework was progressing well and it should be submitted for approval in April 2016 as planned. NHS England had the resource for next year to begin work streams on prevention, earlier diagnosis, research and innovation, data and audit, and living well. It was likely there would be a separate work stream on implementing the commissioning framework. The working groups offered the sector considerable opportunity to make sure the action plan was implemented and raise the profile of hearing loss.
7. Since the decision of the National Screening Committee not to recommend an adult hearing screening programme, work had continued to increase the number of people who were screened. For example, Action on Hearing Loss was working to increase the amount of screening done in care homes.

Sexual and reproductive health

8. Katherine O'Brien from the [British Pregnancy Advisory Service](#), Rubbena Aurangzeb-Tariq from [Deafax](#), and Paulina Ewa Sporek from [Deaf Nest](#) made a presentation about how the Group could help improve access to sexual and reproductive health information for people who were deaf or had a hearing loss.
9. Young D/deaf ('Deaf' is a cultural label that refers to people who are profoundly deaf, whose first or only language is BSL and usually see themselves as part of a cultural and linguistic minority known as the Deaf community; 'deaf' refers to people who have a hearing loss or are deafened) people did not receive the information at school they needed to lead happy, healthy relationships, putting this group at risk. Deaf people told

them they faced significant barriers to accessing healthcare services, and national data showed the D/deaf community experienced higher rates of unplanned pregnancy and STIs than the rest of the population.

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

Sex and relationships education

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

12. There were nearly 38,000 Deaf children in England and over 80 per cent attended mainstream schools.

13. A significant minority (17 per cent) of the D/deaf young people surveyed by bpas and Deafax did not receive SRE lessons in school. The around 200 people surveyed used various communication methods and languages, including English, BSL and Sign Supported English.

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

- a. 40 per cent were not taught about pregnancy;
- b. nearly half (46 per cent) were not taught about STIs; an
- c. over one-third (34 per cent) were not taught about puberty.

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

16. D/deaf young people had a poor understanding of sexual health issues, contraception, and where to go for advice. Issues identified as particularly problematic for D/deaf young people were
- a. delivery – inaccessible written materials with no visual communication; and
 - b. 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

17. D/deaf young people lacked knowledge about where to go for sexual health advice, and where their nearest sexual health service was. As a result, many relied on the internet to provide them with essential healthcare information.
18. Only half of those surveyed by bpas and Deafax felt comfortable seeking medical advice from a clinic. Barriers to accessing support at clinics included worries about communicating with medical staff, difficulties understanding written information, and poor provision of communication professionals at appointments.
19. 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

20. At a time when maternity services in the NHS were aspiring to deliver safe high quality maternity care for all women, the challenges of delivering equitable care to women who were deaf or had a hearing loss as a challenge that needed 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 would be empowered and more confident in accessing midwives and health care professionals. This would in turn result in women having a positive birth experience as well as healthier and better outcomes.

Key findings

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

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

22. D/deaf women were disadvantaged in terms of access to the information and care they needed, from understanding how to protect themselves from STIs to knowing where to turn if they had a concern or question about their pregnancy. This would have a significant impact on this group of women's health, wellbeing and safety.

Possible actions

23. The group urged the APPG to help make sure

- a. deaf awareness training was included in professional education, particularly midwives and similar;
- b. there was accessible guidance for deaf people; and
- c. clinical pathways for deaf pregnant women were developed.

24. The National Deaf Children's Society was planning a campaign on sexual and reproductive health for deaf young people. They would work with the group.

25. The group would contact NHS England regarding the accessible information standard, which made it a requirement to identify, record and meet the communication needs of disabled people.

Any other business

26. Julie Ryder, Director at HearFirst, contacted the Group to offer support for a Deaf Awareness Week (2-8 May) Parliamentary event. As Deaf Awareness Week was the same week as the local elections, the Group thought a Parliamentary event would not be well attended.

Next meeting

27. Jill Jones of DEXperience (Deaf Ex-mainstreamers) contacted the chair about the Group's proposed inquiry into the cost of recognising BSL as a minority language. Jill requested space at the next meeting to speak about the planning of the inquiry. As the Group had agreed to conduct the inquiry later in this Parliament, once the BSL (Scotland) Act, the Action Plan on Hearing Loss and similar had been in place for a while, Jill would be asked to present at a meeting later in the Parliament.

28. The secretariat would contact Members to ask if they were able to attend a meeting in late May. If so, the Group would have a short meeting to review progress on actions.

29. The Group would have a longer meeting in July. It would review progress for the year and decide on a strategy for 2016/17.

Review of progress

1. At the extraordinary general meeting on 30 June 2015 the Group agreed its work programme for the Parliament. It would focus on the following, in order of priority
 - a. subtitles;
 - b. provision of hearing aids;
 - c. awareness of deafness and hearing loss;
 - d. adult education and employment; and
 - e. an inquiry into the cost of minority language recognition for BSL.

Subtitles

2. At the 15 September 2015, Paul Breckell, chief executive of Action on Hearing Loss, spoke to the group about its SubtitleIt! campaign. The campaign aims for the Government to introduce legislation to make access to video-on-demand mandatory.
3. Lilian Greenwood's Private Members' Bill, which aimed to amend the 12 year old Communications Act (2003), was unsuccessful. And in April 2016 the Government announced it would not introduce legislation.
4. The Government believes enough progress is being made to improve subtitles on video-on-demand services. However
 - a. only 22 of the 90 on-demand service providers offer subtitles (an increase of only five since 2014);
 - b. only 4 of the 90 on-demand service providers offer sign language translation;
 - c. 85 per cent of Sky's on-demand content via their set-top box is inaccessible;
 - d. there is no subtitling provision on Sky Go;
 - e. just one of the 21 on-demand services offered through Virgin Tivo have subtitles; and
 - f. only 3 of 12 on-demand services offered through YouView have subtitles.

Provision of hearing aids

5. The January 2016 meeting was told all CCGs had paused their consultations about reducing access to hearing aids pending publication of the NHS England commissioning guidance. North Staffordshire was going ahead with its cuts and the risk of further rationing remained.
6. The commissioning guidance will be published in July 2016. The APPG is working with NHS England on a programme of events to increase awareness of and compliance with the guidance amongst commissioners.

Awareness of deafness and hearing loss

7. In June 2015 the Group reaffirmed its support for the hearing screening campaign. In January 2016 the Group was informed the National Screening Committee had not recommended an adult hearing screening programme. It would not review the decision for four years.
8. In April 2016 the Officers met with the Minister of State for Community and Social Care. They told the Minister the decision of the National Screening Committee was a missed opportunity. The challenge and the costs to the taxpayer were too great to wait the five or so years it would take to conduct a randomised control trial of screening. A programme would also
 - a. add to the data on the effectiveness and uptake of hearing aids;
 - b. add to the data about people who are deaf or have a hearing loss;
 - c. help to determine the best method of screening, as the newborn hearing screening programme did; and
 - d. increase awareness of deafness and hearing loss, and their impact.
9. The Minister asked when there was last a Parliamentary debate about deafness and hearing loss. He suggested the Chair proposed a debate to coincide with the publication of the commissioning guidance in July. The Chair is discussing the debate with the Speaker's office.
10. The secretariat has been consulting colleagues in the sector about a nationwide public health campaign about deafness and hearing loss. They have received confirmations

of support from RAD, The Ear Foundation, Auditory Verbal, Signhealth, NADP, ATLA, Scottish Council on Deafness, Action on Hearing Loss and Action Deafness. Nobody has disagreed with it, although some have said they feel it is an ambitious aim that could be difficult to achieve. Further consultation will take place at a meeting in June.

Adult education and employment

11. At the January 2016 meeting, 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.

12. 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.

13. The Group also heard from Molly Berry of the Association of Teachers of Lipreading to Adults (ATLA). Lipreading classes are vital but availability is patchy.

14. The Group agreed adult education and access to lipreading classes would be included in the briefings for a Westminster Hall debate about deafness and hearing loss. Members agreed to ask Parliamentary Questions about adult education with respect to deafness, and lipreading classes.

Inquiry into the cost of minority language recognition for BSL

15. At the June 2015 meeting, the Group agreed the inquiry needed to be done in this Parliament. However, it would be wise to wait for the BSL (Scotland) Bill to be enacted and monitor its impact.

Actions

16. Members should discuss progress against its work programme and decide what may need to be done in 2016/17. In particular, Members may want to

- a. discuss what it might do next to make sure more subtitling is provided for video on demand;
- b. discuss how the NHS England commissioning guidance could be communicated to commissioners; and
- c. indicate whether they support the suggestion of a nationwide public health campaign about deafness and hearing loss.