

# Access to health services for deaf people

June 2015



# Health Committee Members

Onkar Sahota (Chair)	Labour
Andrew Boff (Deputy Chair and Rapporteur)	Conservative
Kit Malthouse MP	Conservative
Murad Qureshi	Labour
Valerie Shawcross CBE	Labour

## Role of the Health Committee

The Health Committee is tasked with reviewing health and wellbeing across London, including progress against the Mayor's Health Inequalities Strategy. The Committee will consider the Mayor's role as Chair of the new pan-London Health Board and the impact that recent health reforms are having on the capital, notably NHS reconfiguration and the decision to devolve public health responsibilities to local authorities.

The GLA Oversight Committee approved the appointment of Andrew Boff as the Rapporteur for the Health Committee in March 2014. The following terms of reference for the Rapporteurship were agreed by the Health Committee in June 2014:

To review access to health services for D/deaf and hard of hearing people to:

- Identify key elements of an accessible health service model for D/deaf and hard of hearing people;
- Explore the challenges health service providers face in improving access for D/deaf and hard of hearing people, and how they might be overcome;
- Explore what levers the Mayor could employ to promote and support improved access to health services for D/deaf and hard of hearing people; and,
- Recommend practical changes that can be made towards making health service provision more accessible to D/deaf and hard of hearing people.

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## Foreword

It is a shocking fact that deaf people are more likely to suffer ill health than other people, simply because it is harder for them to use the health services that many of us take for granted. Deaf people are twice as likely to have high blood pressure, four times more likely to develop diabetes and generally have a reduced life expectancy. This is unacceptable and has to change.



I certainly take for granted the fact that I will be able to communicate easily with health service staff – booking an appointment through a receptionist, discussing treatment options with my GP, or understanding a diagnosis from a hospital consultant.

But this is not the experience for many deaf people, and it can be so frustrating and difficult that some simply don't use our health service. Those who do use it often have a much poorer experience than others might.

It is so disappointing that the situation doesn't seem to have improved in the last twenty years. Even the passing of the Equality Act 2010, which should protect deaf people from discrimination and require service providers to make reasonable, proactive adjustments, has not made a significant difference to the experience of deaf people.

An important first step would be to collect better data on the number of deaf people in London. It is incredible that estimates for London's deaf population range as widely as 25,000 to one million. How can communication support services be commissioned to meet the needs of London's deaf population if we do not understand the scale and nature of that demand?

We need to lobby for improved access, in a co-ordinated and systematic way, in order to place the needs of deaf people firmly on the agenda. We hope this report will help bring stakeholders together, so they can bring their collective pressure on local Health and Wellbeing Boards to take the needs of deaf people more seriously.

Issues with access are entirely avoidable and this report suggests some practical and workable solutions for healthcare professionals. I want to build on the growing momentum for change. The injustices deaf people have to

battle against when accessing the health service need to be urgently addressed.

A handwritten signature in black ink, appearing to read 'Andrew Boff', written in a cursive style.

**Andrew Boff AM**  
**Rapporteur for the Health Committee**

## Executive summary

Deaf people in London are more likely to suffer ill health than the rest of the population, largely because they face problems accessing health services that should be available to all. Basic interactions, like making an appointment, or getting advice from a doctor, are harder for those with hearing loss, and this is putting deaf people off making use of the health services they are entitled to. Despite the passing of the Equality Act 2010, health service providers have still not tackled the inequality in access that disadvantages deaf people in London.

We do not know how many people in London suffer from hearing loss; estimates range from approximately 25,000 to over one million. Without more accurate data, health commissioners and providers cannot understand the scale and variety of needs among London's deaf population. We therefore recommend that NHS England London should take the lead in collecting better data on hearing disability in London. As part of this, Public Health England should update the 20-year old research on hearing loss prevalence among the general population.

It is obvious that, for the deaf person, good quality communication is the key factor in determining how easily they can access their GP or hospital, and we highlight a number of areas for improvement:

- We recommend that local Clinical Commissioning Groups should work together – perhaps at a pan-London level – to commission the communication support services that deaf people need. We believe that, as well as improving the level and standard of these services, joint commissioning would reduce costs for the health service.
- We note that there are not enough British Sign Language (BSL) interpreters to ensure a consistent standard of service at health appointments, and we recommend that stakeholders agree a minimum BSL standard for support services in health settings.
- We conclude that all health staff need deaf awareness training appropriate to their role. It is important that staff receive this training periodically to ensure that they keep their knowledge and skills up-to-date.
- Building on the conclusions from our previous report, *Access to GP care*, we note that GPs and hospitals need to make better use of digital solutions to make it easier for deaf patients to access health services.

Deaf people may be put off complaining about the service they receive because of the complicated complaints process and the lack of advocacy support available. This means that health providers are not always aware of the problems that deaf people are encountering.

Throughout this report we will use deaf with a capital 'D', to identify individuals who are profoundly deaf, who were born deaf or became deaf at an early age, would describe themselves as culturally deaf, and whose first language is British Sign Language. We will identify individuals with mild hearing loss, through to severe loss with a small 'd', and will also use this when referring to the deaf population as a whole, including profoundly Deaf individuals.

# 1. Introduction

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Ten million people in the UK have some form of hearing loss,<sup>1</sup> ranging from mild loss to being profoundly deaf.<sup>2</sup> These people face a range of barriers and problems in accessing the health service, with damaging effects on their health and wellbeing. Through this investigation, we hope to raise the profile of this important issue, generate momentum for change, and highlight some practical solutions that can be implemented.

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## The barriers to health services

- 1.1 Deaf people can be at a disadvantage in making full use of health services in London. They can find many basic aspects of access difficult, such as making an appointment, understanding how to take their medication, or receiving advice on options for treatment.<sup>3</sup> The rest of the population will take these and other interactions with health professionals for granted. Recent research into the experiences of Deaf people found that almost half found contact with their GP 'difficult' or 'very difficult', and a third thought it wasn't worth seeing their GP because communication was poor.<sup>4</sup> These findings and experiences are replicated among all people who experience hearing loss, and with the evidence we collected during this inquiry.<sup>5</sup>
- 1.2 Good communication is probably the singular most vital component of improved access but it continues to be a major barrier. Providers generally seem to lack awareness and understanding of the range of communication support deaf patients might need, the options available to address those needs, and how they might make services more accessible to the deaf user.<sup>6</sup>

*"I have just visited a deaf friend in hospital. She couldn't understand what the doctors were saying and no communication support was available to her."*

*"My deaf daughter had to go for a pregnancy check up and the midwife didn't know anything about interpreters or how to get one, or even who would get one."*

*"I am a good lipreader, but I know people have difficulties understanding my voice, so I take a friend with me when I go to the GP... Only one of them has ever looked at me when they are answering my questions."*



### The consequences of poor access for deaf people

- 1.3 Poor access to health care has a negative impact on the health and wellbeing of deaf people. Recent research concluded that

*“Deaf people’s health is poorer than that of the general population, with probable under-diagnosis and under-treatment of chronic conditions, putting them at risk of preventable ill health.”<sup>7</sup>*

The research also found that just under half of all the deaf people in the study sample were in a high risk group for serious illness, and that they had higher rates of obesity than the general population. Other research shows that high blood pressure is more common in Deaf people, and proportionately more cases go undetected, or are insufficiently treated. Deaf people are also twice as likely to have high blood pressure, four times more likely to develop diabetes, and generally have reduced life expectancy.<sup>8</sup> In short, deaf people are more likely to suffer ill health than the hearing population – primarily as a result of the entirely avoidable difficulty in accessing services.

### Time for change

- 1.4 People with hearing loss have long campaigned for the same level of access to health services that hearing people receive. For some, accessing their local GP or hospital remains as much a challenge now as it did 20 years ago. The Equality Act 2010, which is the legal framework that should protect deaf people from discrimination, is not yet having the required effect. It requires service providers to make reasonable, proactive, adjustments to improve the accessibility of their services to people who are disabled. But previous research and the evidence we have heard suggest that adjustments made to accommodate people with hearing loss are reactive and being implemented in a piecemeal way.<sup>9</sup> As a result of this ongoing failure, deaf people increasingly have to enlist the media to highlight the challenges they face, or are taking their concerns all the way to the Parliamentary and Health Service Ombudsman (PHSO).<sup>10</sup>

After its Primary Care Trust withdrew funding for a British Sign Language interpreter in 2011, Mrs E’s GP Practice decided it would no longer provide them for appointments. It offered Mrs E longer appointment times and said staff would communicate with her through written notes. Mrs E complained, and ultimately took her case to the PHSO, which decided in her favour. The Practice apologised, paid Mrs E £3,000, and put together an action plan to show how it will meet the needs of Mrs E and other patients with disabilities.

### **The role of the Mayor**

- 1.5 By law, the Mayor must promote the reduction in health inequalities in London and publish a strategy which identifies health inequalities in the capital, priorities for reducing them, and the roles to be played by key partners.<sup>11</sup> Equitable access to high quality health and social care is one of five strategic objectives set out by the Mayor in the London Health Inequalities Strategy, published in April 2010.

### **The purpose of this investigation**

- 1.6 We hope that this investigation, and this report, will help to raise the profile of the challenges deaf people face in accessing health services in London. Our review focuses specifically on access to GPs and local hospitals, but many of our findings are also relevant to other parts of the health system, such as dentists, pharmacists or other community-based providers.
- 1.7 We also hope that this work will provide practical and workable suggestions for improving access for deaf patients, and add to the momentum for change in the way London GPs and hospitals plan and provide services to accommodate their deaf patients.

## 2. The role of data in improving access

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**Accurate data on deaf people in London is urgently needed. The lack of this data makes it difficult for commissioners of health services, and those in the front line of delivery, to plan and provide services that meet the needs of deaf patients. Official data, last collated in 2010, underestimates the true number of deaf people in London, meaning that demand for relevant services is outstripping supply. NHS Equality and Diversity Monitoring forms can be adapted to help provide this data.**

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- 2.1 There is no widely accepted estimate for the number of deaf people in London. In a society awash with data, this is a shocking gap, and a clear weakness in the health system's ability to allocate its scarce resources properly. According to the latest official data, published in 2010, there are around 25,000 deaf people in London. Of this number, two thirds (about 17,000) are small 'd' deaf, and one third (8,000) are capital 'D' Deaf.<sup>12</sup> But other estimates (discussed further below) indicate that there may be more than one million people deaf people in London, including over 80,000 profoundly or severely Deaf people.
- 2.2 It is obvious that health service providers need accurate, granular and timely data to plan and deliver the services that deaf people need in London. It is equally obvious that this data is not available. We can safely say that, without this data, providers do not understand the scale and variety of needs among London's deaf population. Furthermore, because this data is absent, the services for deaf people do not receive an appropriate profile or share of funding and other resources. Deaf people are being systematically disadvantaged and, without an accurate picture of demand for services, we see little prospect of this inequality being removed.
- 2.3 We believe that the responsibility for improving the quality of the data and routinely compiling it sits squarely with NHS England London. An important first step will be to work with representative organisations, such as the British Deaf Association, Action on Hearing Loss, and the National Deaf Children's Society, to establish an approach that will address outstanding questions on methodology, criteria and frequency.

## How to improve the data

- 2.4 Most of the stakeholders we spoke to felt that the work on hearing loss prevalence by Professor Adrian Davis and others<sup>13</sup> would be a good starting point in improving the data. This estimated the percentages of the population (by age band) with hearing loss, and with severe or profound Deafness. Despite being 20 years old, it is still routinely applied to census data and provides – according to Action on Hearing Loss, the BDA and others – a more realistic estimate of the deaf population. Applying the latest prevalence data to the 2013 Office for National Statistics (ONS) population estimates indicate there are one million people deaf people in London, of whom 82,500 are profoundly or severely Deaf. The Davis research was updated in 2007, but would benefit from being updated again – a task that could reasonably be undertaken or sponsored by the Knowledge and Intelligence arm of Public Health England at a national level.<sup>14</sup>
- 2.5 One part of the problem is that there is currently no single approach among public bodies on what identification criteria to apply, and no agreement among stakeholders about how to record deafness.<sup>15</sup> Some prefer to measure it in terms of the degree of hearing loss, while others favour measuring based on the range of communication requirements of deaf people. It may be that either one or a combination of the two will be needed. Either way, it is important that stakeholders agree on the criteria to use so that the data is as useful as possible.
- 2.6 There may be an argument for collecting detailed information on a regular, periodic, basis. The Office for National Statistics (ONS) collected data on British Sign Language (BSL) users for the first time in its 2011 census, and this certainly represents progress. However, the way the question was phrased has led some stakeholders to argue that it underestimated the real number of BSL users, with some fearing this could result in demand being underestimated, and funding cut.<sup>16</sup> This is further evidence of how important it is to collect data in the most methodologically sound way.
- 2.7 We do not claim to have devised a solution for this problem. But we hope that this investigation acts as a stimulus to encourage stakeholders to work together to find a workable and cost-effective way of generating the data that is needed. One option that should be examined further is making better use of NHS Equality and Diversity Monitoring forms. These forms should be updated and improved to provide more detailed information about hearing disability.

### *Equality and Diversity Monitoring*

- 2.8 NHS Equality and Diversity Monitoring forms are not being used to their full potential, and opportunities to collate data on deaf patients are being missed. In recent years, there has been a real focus on capturing data on the range and scope of disabilities. Many forms now give options on the type of disability the individual may wish to record and in some cases, the opportunity to elaborate on that disability, if needed. The list of options vary, depending on the form, but even with an extended list, a deaf individual generally has the option only to identify themselves as either being Deaf or having a hearing impairment.
- 2.9 There is scope for equalities monitoring forms to gather more specific information on hearing disability, allowing the individual completing the form to identify whether they are profoundly Deaf, have severe, moderate or slight hearing loss, and whether they are a BSL user. The more developed and detailed the options are, the better the returned information will be. The NHS England London Clinical Senate Patient and Public Voice Group, working closely with key stakeholders, could lead on work to develop an Equality and Diversity Monitoring template that will provide this vital information.

#### **Recommendation 1**

**Data on hearing disability should be routinely collected and compiled. We recommend that NHS England London take lead responsibility for this, and that it explore with key stakeholders, such as the British Deaf Association, Action on Hearing Loss, and the National Deaf Children's Society, how this might best be done.**

#### **Recommendation 2**

**The earlier work on prevalence data by Adrian Davis et al (1995) should be updated at the earliest opportunity, and is a task that could reasonably be undertaken or sponsored by the Knowledge and Intelligence arm of Public Health England.**

**Recommendation 3**

**The NHS England London Clinical Senate Patient and Public Voice Group should lead on initial work to develop an Equality and Diversity Monitoring template that will allow health service providers to gather more specific information on hearing impairments.**

### 3. Developing consistency in access

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**A range of approaches should be taken to improve patient access and ensure better patient experience and engagement with health service providers. There is potential for local Clinical Commissioning Groups to jointly commission the communication support needed to improve the deaf patient's initial and ongoing access to services. Standard minimum levels are needed for deaf awareness training to professional staff and for BSL translating and interpreting support at health appointments. Health care providers need to make better use of technology to improve access for deaf patients.**

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- 3.1 For the deaf person, quality of communication is the key factor regarding the ease of access to their GP or local hospital. Good communication options need to be available right from the start of the process, but this is not always the case. We have identified a number of factors that inhibit good communication and therefore limit access to health services for deaf people.

#### **Joint commissioning**

- 3.2 The way that communication support to deaf patients in London is commissioned does not always work effectively, and is contributing to the variation in access to services. Commissioners – usually the local Clinical Commissioning Group (CCG) for communication support provided through GPs and hospitals – are able to focus on the needs of their local population.<sup>17</sup> But there is a strong argument in favour of more joint commissioning across CCGs or even at a pan-London level. We agree with the conclusions of the NHS England Action Plan on Hearing Loss, published earlier this year, which recognises the need for *“improving both the commissioning and integration of services”*, and we think this applies equally to services for the deaf population.<sup>18</sup>
- 3.3 A joint or, ideally, a pan-London approach would enable CCGs to provide a strategic response to planning and delivering services across a much wider geographical area, and for the benefit of much larger numbers of deaf people. Commissioners would be able to maximise the cost advantages that come from operating on a larger scale, and ultimately deliver improved outcomes for deaf people. A focal point that both service users and providers can revert to would help to address uncertainties that can arise locally about who is responsible for arranging or paying for the support. There are joint

commissioning models elsewhere in the country and internationally that could be applied to London.

Commissioned across two CCGs, Action on Hearing Loss (AOHL) has provided communication support to deaf patients in Merseyside since June 2013. The service provides BSL interpreters, deafblind interpreters, lipspeakers and notetakers for people with hearing loss who attend GP appointments in Liverpool, Sefton, Knowlsey, Halton and St Helens. AOHL ensure appropriately qualified professionals by sourcing them through the National Registers for Communication Professionals working with Deaf and Deafblind People (NRCPD).

### Minimum standards for BSL interpreting support

- 3.4 There are simply not enough BSL interpreters to ensure a consistent standard of service at health appointments. There are fewer than one thousand BSL interpreters registered with the NRCPD in the UK.<sup>19</sup> A 2012 survey of BSL users found that two out of three Deaf patients who asked for an interpreter at a hospital appointment did not receive one.<sup>20</sup> Even among those who did have an interpreter, almost half were unhappy with the service they received. This may indicate that not all BSL interpreters at health appointments are appropriately qualified and registered.
- 3.5 One of the main reasons for the low numbers of BSL interpreters is the length of time and expense involved in becoming fully qualified. There are currently six levels of training to complete, which can take seven or eight years in total. Furthermore, because of reductions in local authority grants and community funding, students increasingly have to fund themselves or seek sponsorship, possibly from their employer.<sup>21</sup>
- 3.6 Stakeholders and health service providers do not always agree on what level of BSL qualification is needed to support deaf patients at appointments. One provider told us that they would use interpreters qualified to Level 4. The London Borough of Islington in-house interpreting service only uses Level 6 interpreters – the highest level of qualification. The BDA and other support organisations are clear that a Level 6 qualification in both the language and skill of interpreting is needed to provide an appropriate level of support.
- 3.7 We agree with the stakeholders we have received evidence from that a minimum BSL interpreting standard needs to be applied to support provided in health settings. This would remove any doubt about what constitutes an



acceptable level of support, and provide a clear measure against which to benchmark the providers' obligation under the Equality Act 2010. We are not in a position to recommend a specific level of qualification. That work should be led by NHS England working in partnership with key stakeholders such as the NRCPD, the BDA and Signature.

### Deaf awareness training

- 3.8 Deaf awareness training needs to be a key part of professional and support staff training in the health sector. Encouraging front line health staff to make simple changes can make huge improvements to the experiences of deaf patients. These changes can be as easy as asking reception staff to ensure that their face and mouth are clearly visible, for example by standing up from their desk.
- 3.9 Training obviously needs to be proportionate to specific roles and the frequency of contact with deaf service users. Stakeholders suggested that a short online training course might be sufficient for many staff. For those staff who would be in regular contact with deaf patients (such as those working in an audiology department) more intensive training lasting several days would be necessary. All training would need to be refreshed periodically to ensure that staff maintain their knowledge levels and ensure that they can provide deaf patients with the same level of service they do for other patients.

### Maximising technology use

- 3.10 GPs and hospitals need to make better use of the range of digital solutions available to facilitate easier access for deaf patients. While this is an issue that affects the level of service for all patients, evidence suggests that the impact is more severe among deaf patients. For example, in 2014, just under half of Deaf BSL users could only make an appointment to see their GP by physically going in to the practice. Technological assistance for deaf patients does not have to be expensive. Online interpreting services, for example, can be accessed at approximately £2.50 per minute, and could be used to supplement the work of traditional BSL interpreters.
- 3.11 In our 2015 report, *Access to GP care*, we recommended that 'enabling digital capability' should be integral to the work of NHS England London to transform primary care in the capital.<sup>22</sup> We are therefore pleased to see some signs of progress, such as a rapid increase in capability for patients to book appointments with their GPs online, which is now up to 97 per cent in England (up from just 3 per cent in April 2014).<sup>23</sup>

**Recommendation 4**

**Local Clinical Commissioning Groups should jointly commission communication support services to deaf patients to improve the level and standard of these services, achieve economies of scale and stimulate a more competitive market.**

**Recommendation 5**

**We recommend a universal minimum standard for British Sign Language interpreting support provided in healthcare settings. Work to determine the appropriate standard to be applied should be led by NHS England working in partnership with the National Registers for Communication Professionals working with Deaf and Deafblind People and other key deaf support organisation such as the British Deaf Association and Signature.**

## 4. Making it easier to complain

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**Simplifying the complaints process will improve access. Poor access often goes undetected as individuals are put off by an over-complicated complaints system and the absence of any structured advocacy support to help navigate their way around it. Other than through equalities legislation, providers are not currently held to account for any failure to make their services easily accessible to deaf patients. Establishing accountability through the court process is difficult and costly.**

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- 4.1 Stakeholders have told us that deaf individuals are often reluctant to make a formal complaint when the service they have received is not up to standard. The process itself can be confusing and difficult, with information and guidance hard to find. In addition, the loss of community-based advocacy and advice, to help navigate an individual through the process and to help access the appropriate communication support, is also a big concern.

### **Navigating the complaints process**

- 4.2 A formal complaint follows a two-stage process. At the first stage, a complaint can be made to the service provider (GP or hospital) or commissioner of those services (the local CCG or NHS England, respectively). The complainant can opt to ask someone else to submit the complaint on their behalf. If the complainant is unhappy with the outcome of their complaint at the first stage, there is the option to take it to the PHSO.
- 4.3 These seemingly simple steps, when unpacked from a practical perspective reveal a process that can be difficult and inconsistent. To start with, information on how to make a complaint is not generally well signposted. It can be difficult to find the relevant information on GP Practice, hospital and NHS England websites, which is often lying several clicks away from the homepage.<sup>24</sup>
- 4.4 The prospect of scrolling through several text-dense web pages in order to work out how to make a complaint can be a particularly daunting prospect for a deaf person. The London Borough of Islington's in-house Interpreting Service pointed out that many Deaf sign language users have restricted literacy in English. Web pages tend to be text-dense and are not offered in 'easy read format' or in an alternative communication format, such as BSL.

There is also a widely held assumption that BSL provides a literal translation of written or spoken English, which is not the case.

- 4.5 Formal complaints made to service providers are generally required to be submitted in writing. Guidance set out on the NHS England website gives three possible options, two of which involve a written submission – by post or by email.<sup>25</sup> The third option involves making a telephone call to NHS England’s Customer Contact Centre.
- 4.6 The potential for a breakdown in official support mechanisms throughout the process can add to the stress of making a complaint. Take the example of a complaint about hospital services. In the hospital, Patient Advice and Liaison Services (PALS) work with and guide the complainant, typically offering advice and support where needed, and a liaison point between the individual and hospital personnel. But, as we were told, *“There is a lack of understanding, or when you arrive at a PALS team, they can’t communicate with you.”*<sup>26</sup>

#### Advocacy and advice

- 4.7 Our understanding is that deaf people are finding it increasingly difficult to access advocacy and advice services. Where services are available, they may not always suit the deaf person’s specific advocacy needs or may be difficult to access because of the range of organisations one might need to navigate to identify the right service.<sup>27</sup>
- 4.8 Under the Health and Social Care Act 2012, responsibility for commissioning advocacy and advice support through the complaint process now rests with the local authority.<sup>28</sup> The NHS England Complaints Policy confirms that:

*“Since April 2013, individual local authorities have a statutory duty to commission independent advocacy services to provide support for people making, or thinking of making, a complaint about their NHS care or treatment. Arrangements will vary between local authority areas.”*<sup>29</sup>

The lack of advocacy support has also been raised as an issue for concern by stakeholders participating in other reviews by the London Assembly Health Committee, such as its review of mental health service provision in London for young people and Black Asian and Minority Ethnic Groups.

- 4.9 Reduced access to advocacy and advice support also presents challenges for those individuals who want to enforce the legal requirements of the Equality Act 2010. The legal process is lengthy and costly. The absence of advocacy representation is deterring deaf patients from pursuing this avenue.

- 4.10 The Act, stakeholders told us, is a valuable framework, but needs to be accompanied by guidance that clearly explains the requirement to make 'reasonable adjustments'.<sup>30</sup> The present lack of case law to provide some guidance makes it more difficult to hold providers to account.

#### **Recommendation 6**

**NHS England must commission a review of advocacy services for deaf people. As part of this, NHS England must establish whether local authorities are fulfilling their responsibility to commission advocacy services under the Health and Social Care Act 2012.**

#### **Simplifying the complaints system**

- 4.11 Poor signposting of the complaints process, coupled with the frustrations perpetuated by the challenge of navigating an often convoluted pathway, is resulting in deaf individuals either succumbing to barrier-fatigue and giving up, or escalating their concerns through the media and/or the PHSO. Deaf patients should not have to resort to this.
- 4.12 A consistent and simplified complaints process is needed. In the short term, there are some simple, low-cost steps that could be taken. The link to information on how to make a complaint needs to be brought forward to the home page of the GP or hospital website. Information also needs to be made available in an 'easy read' format.
- 4.13 The help that some deaf people need to navigate the complaints system is, by its nature, different from the help that other people require – and it is not always consistently available to them. As we have said in paragraph 3.3, we think that there are clear benefits from local CCGs joining together to commission support services for deaf people; this should also include services to help deaf people to make complaints. As well as trained and qualified support staff, this could include specialist online support in line with the wider agenda to make better use of technology to facilitate patient access.

#### **Recommendation 7**

**We recommend that London GPs and NHS Trusts review the accessibility of information on their complaints process for deaf patients, with a view to providing a direct link on the home page of their websites. They should also provide alternative formats of this information, which should include an 'easy read' format.**

**Recommendation 8**

**When local Clinical Commissioning Groups commission communication support services for deaf patients – either jointly (as per recommendation 4) or individually – they should ensure those services include appropriate means of supporting deaf people through whatever complaints processes they need to navigate. NHS England London should provide guidance on what those ‘appropriate means’ might involve.**

## 5. Lobbying for change

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**A number of stakeholders are working hard to bring about change to improve access for deaf people. These efforts need to be coordinated more effectively to lobby local Health and Wellbeing Boards and NHS England London for service improvements.**

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- 5.1 There is a clear understanding and recognition among deaf health service users and support organisations that their lobbying for improved access has lacked the cohesion and momentum needed to place it firmly on the political agenda. Delegates who attended the seminar event hosted by the rapporteur as part of our investigation recognised that they need to be more cohesive and systematic in lobbying for their cause.<sup>31</sup>
- 5.2 The political profile on deaf access issues has, until recently, remained relatively low at both regional and national level despite the wealth of available research. But a change in pace is evident from the work being done through local Healthwatch, as it begins to prioritise and promote the need for improved access locally. Stakeholders need to work together to ensure that local Health and Wellbeing Boards take their concerns seriously and put the needs of deaf patients on their agendas.
- 5.3 Good practice is happening across London, such as the London Borough of Islington in-house interpreting service, and nationally, as seen from the joint commissioning model in place in Merseyside. But these examples of good practice tend not to be shared or applied more widely. A strategic overview and understanding of the support needs for deaf people, not just in accessing health services but for continuing treatment is needed. As the regional overseer of health service provision, it is now time for NHS England London to build on existing national work, such as the national Action Plan on Hearing Loss and development of an Accessible Information Standard. Specifically for London, NHS England should look at ways it might work with London GPs and hospitals to realise a universal standard for access to health services for deaf people, and develop a mechanism for sharing the good practice that is already happening across London.

**Recommendation 9**

**NHS England London should work with London GPs and hospitals to develop a universal standard for access to health services for deaf people, and draw up a plan to share the good practice that is already happening across London.**



## Appendix 1 – Recommendations

1. Data on hearing disability should be routinely collected and compiled. We recommend that NHS England London take lead responsibility for this, and that it explore with key stakeholders, such as the British Deaf Association, Action on Hearing Loss, and the National Deaf Children’s Society, how this might best be done.
2. The earlier work on prevalence data by Adrian Davis et al (1995) should be updated at the earliest opportunity, and is a task that could reasonably be undertaken or sponsored by the Knowledge and Intelligence arm of Public Health England.
3. The NHS England London Clinical Senate Patient and Public Voice Group should lead on initial work to develop an Equality and Diversity Monitoring template that will allow health service providers to gather more specific information on hearing impairments.
4. Local Clinical Commissioning Groups should consider jointly commissioning communication support services to deaf patients to improve the level and standard of these services, achieve economies of scale and stimulate a more competitive market.
5. We recommend a universal minimum standard for BSL interpreting support provided in healthcare settings. Work to determine the appropriate standard to be applied should be led by NHS England working in partnership with the National Registers for Communication Professionals working with Deaf and Deafblind People and other key deaf support organisation such as the British Deaf Association and Signature.
6. NHS England must commission a review of advocacy services for deaf people. As part of this, NHS England must establish whether local authorities are fulfilling their responsibility to commission advocacy services under the Health and Social Care Act 2012.
7. We recommend that London GPs and NHS Trusts review the accessibility of information on their complaints process for deaf patients, with a view to providing a direct link on the home page of their websites. They should also provide alternative formats of this information, which should include an ‘easy read’ format.
8. When local Clinical Commissioning Groups commission communication support services for deaf patients – either jointly (as per recommendation 4) or individually – they should ensure those services include appropriate

means of supporting deaf people through whatever complaints processes they need to navigate. NHS England London should provide guidance on what those 'appropriate means' might involve.

9. NHS England London should work with London GPs and hospitals to develop a universal standard for access to health services for deaf people, and draw up a plan to share the good practice that is already happening across London.

## Appendix 2 – How the review was carried out

### Stakeholder meetings

The rapporteur, Andrew Boff, met with the following stakeholders:

- **Dan Sumners**  
Senior Policy Officer, Signature
- **David Buxton**  
Chief Executive, British Deaf Association
- **Edward J Richards**  
Self-advocate with extensive experience of working with health service providers to reduce the communication barriers deaf people face.
- **Matthew James**  
Programme Lead, NHS England Advisory Group on improving experiences for deaf patients
- **Merfyn Williams**  
Self-advocate with extensive experience of working with health service providers to reduce the communication barriers deaf people face.
- **Paul Breckell**  
Chief Executive, Action on hearing loss
- **Professor Bencie Woll**  
Director, Deafness, Cognition and Language Research Centre, University College London
- **Steve Powell**  
Chief Executive, Signhealth

Andrew Boff also accepted an invitation to participate in the NHS England Advisory Group on improving experiences for deaf patients. An initial meeting took place in February 2015.

### Site visits

Andrew Boff visited the following organisations, to understand how their services have helped improved access for deaf people, and what specific features might be replicated on a wider scale, to help provide an accessible service model of provision:

- London Borough of Islington Sign Language Interpreting Service

- Royal Free London NHS Foundation Trust

#### **Written contributions**

- Ealing Clinical Commissioning Group
- Guys and St. Thomas' NHS Foundation Trust
- Islington Clinical Commissioning Group
- Katy Judd, Consultant Nurse
- Healthwatch Ealing
- Healthwatch Islington
- Healthwatch Southwark
- London Borough of Islington
- Southwark Clinical Commissioning Group
- Tower Hamlets Clinical Commissioning Group
- Wandsworth Clinical Commissioning Group

#### **City Hall Seminar**

Andrew Boff hosted a half day seminar on 2 October 2014, to explore challenges faced by health service providers to provide an accessible service, and the levers open to the Mayor to promote and support improved access. The seminar was attended by 44 delegates, representing health care providers and service users.

#### **Literature review**

The Scrutiny Manager undertook a desk-based review of annual surveys published by Action on Hearing Loss, and other research and publications, including work by the British Deaf Association, Signhealth, and local Healthwatch organisations.

## Appendix 3 – Defining deafness

Hearing loss is measured by finding the quietest sounds someone can hear by using tones with different frequencies, which are heard as different pitches. The level at which a person hears a tone is called the threshold. Thresholds are measured in units called dBHL – dB stands for ‘decibels’ and HL stands for ‘hearing level’. Anyone with thresholds between 0 and 20 dBHL across all the frequencies is considered to have ‘normal’ hearing. The quietest sounds a profoundly deaf person can hear average 95 decibels or more.

*Mild hearing loss* – People with mild hearing loss can have some difficulty following speech, mainly in noisy situations. The quietest sounds they can hear average between 25 and 39 decibels.

*Moderate hearing loss* – People with moderate hearing loss may have difficulty following speech without hearing aids. The quietest sounds they can hear average between 40 and 69 decibels.

*Severe hearing loss* – People with severe hearing loss rely a lot on lip-reading, even with hearing aids. BSL may be their first or preferred language. The quietest sounds they can hear average between 70 and 94 decibels.

*Profound deafness* – British Sign Language may be the first or preferred language for people who are profoundly deaf, or they might communicate by lip-reading.

### Everyday terms used to describe deafness

*People who are deaf* – People with all degrees of hearing loss.

*People who are hard of hearing* – People with mild to severe hearing loss and, who have lost their hearing gradually.

*People who are deafened* – People who were born hearing and, became severely or profoundly deaf after learning to speak.

*People who are deafblind* – People who may have some hearing and vision or, could be totally deaf and totally blind.

*The Deaf community* – People whose first or preferred language is British Sign Language (BSL) and consider themselves part of the Deaf community. They may describe themselves as Deaf with a capital D to emphasise their Deaf identity.

*Source: Action on Hearing Loss*

## Appendix 4 – Endnotes

<sup>1</sup> Action on Hearing Loss, Access All Areas, April 2012

<http://www.actiononhearingloss.org.uk/supporting-you/policy-research-and-influencing/research/access-all-areas.aspx>

<sup>2</sup> Hearing loss is measured by finding the quietest sounds someone can hear by using tones with different frequencies, which are heard as different pitches. The level at which a person hears a tone is called the threshold. Thresholds are measured in units called dBHL – dB stands for ‘decibels’ and HL stands for ‘hearing level’. Anyone with thresholds between 0 and 20 dBHL across all the frequencies is considered to have ‘normal’ hearing. The quietest sounds a profoundly deaf person can hear average 95 decibels or more.

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*Profound deafness* – British Sign Language may be the first or preferred language for people who are profoundly deaf, or they might communicate by lip-reading.

<sup>3</sup> Signhealth, Sick of it, March 2014, <http://www.signhealth.org.uk/health-information/sick-of-it-report/>

<sup>4</sup> Forty-four per cent of Deaf patients found contact with their GP ‘difficult’ or ‘very difficult’ and 33 per cent could not easily arrange an appointment. Signhealth, [Sick of it](#), March 2014

<sup>5</sup> London Assembly Health Committee, [Access to health services seminar](#), 2 October 2014.

<sup>6</sup> Quotes taken from Signhealth, Why are you still missing me?, September 2009 [www.signhealth.org.uk/v3/wp-content/uploads/2014/10/Why-Are-You-Still-Missing-Me.pdf](http://www.signhealth.org.uk/v3/wp-content/uploads/2014/10/Why-Are-You-Still-Missing-Me.pdf)

<sup>7</sup> The current health of the signing Deaf community in the UK compared with the general population: a cross-sectional [study](#), BMJ, January 2015

<sup>8</sup> Signhealth, [Sick of it](#), March 2014

<sup>9</sup> RNID, A Simple Cure, December 2004, [www.signhealth.org.uk/health-information/sick-of-it-report/](http://www.signhealth.org.uk/health-information/sick-of-it-report/); Signhealth, Why are you still missing me? September 2009, [www.signhealth.org.uk/v3/wp-content/uploads/2014/10/Why-Are-You-Still-Missing-Me.pdf](http://www.signhealth.org.uk/v3/wp-content/uploads/2014/10/Why-Are-You-Still-Missing-Me.pdf); Action on Hearing Loss, Access All Areas, April 2012, [www.signhealth.org.uk/v3/wp-content/uploads/2014/10/Why-Are-You-Still-Missing-Me.pdf](http://www.signhealth.org.uk/v3/wp-content/uploads/2014/10/Why-Are-You-Still-Missing-Me.pdf)

<sup>10</sup> For example, see [www.ombudsman.org.uk/make-a-complaint/case-summaries/volume-2/health/deaf-patient-denied-access-to-bsl-interpreter-at-gp-practice](http://www.ombudsman.org.uk/make-a-complaint/case-summaries/volume-2/health/deaf-patient-denied-access-to-bsl-interpreter-at-gp-practice)

<sup>11</sup> Section 309, Greater London Authority Act 2007

<sup>12</sup> Health and Social Care Information Centre, People Registered as Deaf or Hard of Hearing - England, Year ending 31 March 2010, [www.hscic.gov.uk/catalogue/PUB00594/peop-regi-deaf-hard-3103-2010-eng-anx.xls](http://www.hscic.gov.uk/catalogue/PUB00594/peop-regi-deaf-hard-3103-2010-eng-anx.xls)

<sup>13</sup> Professor Adrian Davis, Hearing in Adults, 1995

<sup>14</sup> A Davis et al, [Health Technology Assessment: Acceptability, benefit and costs of early screening for hearing disability: a study of potential screening tests and models](#), October 2007

<sup>15</sup> In a meeting with the BDA (29 May 2014), the rapporteur learned that data collation could be based on degrees of hearing loss which do not account for communication requirements, or solely on communication requirements. No universal agreement has been reached.

<sup>16</sup> British Deaf Association [press release](#), March 2013

<sup>17</sup> Information on commissioning arrangements for communication support was requested from all London CCGs in December 2014. Responses were received from Ealing, Islington, Southwark, Tower Hamlets and Wandsworth.

<sup>18</sup> NHS England, Action Plan on Hearing Loss, March 2015, [www.england.nhs.uk/2015/03/23/hearing-loss/](http://www.england.nhs.uk/2015/03/23/hearing-loss/)

<sup>19</sup> As of 31 July 2014, there were 883 registered sign language interpreters plus 265 trainee sign language interpreters. NRCPD, [Annual Report 2013-14](#), page 15.

- <sup>20</sup> Conducted as part of the 'Our Health in Your Hands' campaign coordinated by AOHL and other organisations supporting deaf people.
- <sup>21</sup> Oral submission, by Signature, 16 March 2015
- <sup>22</sup> London Assembly Health Committee, [Access to GP care](#), March 2015, page 20.
- <sup>23</sup> NHS England, [press release](#), 19 May 2015
- <sup>24</sup> Examples include: [University College London NHS Hospital Trust](#); [The Whittington Hospital NHS Trust](#); [Croydon Health Services NHS Trust](#);
- <sup>25</sup> [www.england.nhs.uk/contact-us/complaint/](http://www.england.nhs.uk/contact-us/complaint/)
- <sup>26</sup> Oral submission, by Edward Richards and Merfyn Williams, 22 April 2014
- <sup>27</sup> One example is the interim and subsequent arrangements put in place to support deaf people in Camden, following the closure of the support group [Disability in Camden](#)
- <sup>28</sup> [Health and Social Care Act 2012](#), section 185
- <sup>29</sup> NHS England, [Complaints Policy](#), March 2015, page 11.
- <sup>30</sup> Action on Hearing Loss, stakeholder meeting dated 26 June 2014
- <sup>31</sup> London Assembly Health Committee, [Access to health services seminar](#), 2 October 2014.



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#### Greek

*Εάν επιθυμείτε περίληψη αυτού του κειμένου στην γλώσσα σας, παρακαλώ καλέστε τον αριθμό ή επικοινωνήστε μαζί μας στην ανωτέρω ταχυδρομική ή την ηλεκτρονική διεύθυνση.*

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Bu belgenin kendi dilinize çevrilmiş bir özetini okumak isterseniz, lütfen yukarıdaki telefon numarasını arayın, veya posta ya da e-posta adresi aracılığıyla bizimle temasa geçin.

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यदि आपको इस दस्तावेज़ का सारांश अपनी भाषा में चाहिए तो उपर दिये हुए नंबर पर फोन करें या उपर दिये गये डाक पते या ई मेल पते पर हम से संपर्क करें।

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#### Arabic

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فارجاء الاتصال برقم الهاتف أو الاتصال على  
العنوان البريدي العادي أو عنوان البريدي  
الالكتروني أعلاه.

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