

# WHY ARE YOU STILL MISSING ME?



## **A report following the publication of the GP Patient Survey 2009**

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### A REPORT FOLLOWING THE PUBLICATION OF THE GP PATIENT SURVEY 2009

#### SUMMARY

Deaf people experience huge health inequalities. It is clear that Deaf people do not experience the same health as the hearing population, do not live the same lifestyle and do not have the same access to health services.

The 2009 GP Patient Survey [GPPS] provides further evidence of poor health and poor access for Deaf people. The disparity is sometimes striking. We know that occupation is linked to health. Among Deaf respondents only 30% are in some kind of employment, compared to 50% of the general population. Twenty per cent of Deaf respondents were "sick or disabled" compared to just 6% of the overall population. This exclusion is significant when compared with other sub-groups of the population, such as the Bangladeshi population (43% in employment).

The findings confirm the results from the 2008 GP Patient Survey, which were analysed in "Why do you keep missing me?" (SignHealth: 2008). This year's results show no improvement in Deaf people's life chances. SignHealth will continue to work with health providers to improve services. However, change will only happen when Deaf people demand it.

In the starkest terms, Deaf people are dying earlier than they should. Unless we demand change more Deaf people will die from preventable conditions.

Whatever measure is used, it cannot be disputed that Deaf people are a marginalised group whose needs should be addressed.

The results of the GPPS survey are very revealing but beg more questions than they answer. Focused research is needed to verify these results and provide with certainty the evidence that the findings of the GPPS imply.

*"When it comes to deafness, most health providers have their heads in the sand." (deaf man)*

*"Deafness is the hidden disability and until deaf people demand better healthcare, it will remain out of sight and mind." (Social Worker)*

## INTRODUCTION

SignHealth analysed the results of the 2008 GP Patient Survey. We were concerned that deaf people may not be getting fair access to services. The results showed less satisfaction among Deaf people. Crucially, the results also suggested that Deaf people may be less healthy than hearing people. The charity suspected this was the case, but this was the first national evidence which seemed to prove it.

The 2009 GPPS specifically asked whether the respondent was deaf and used sign language. This was a huge step forward, and we applaud those in the Department of Health and Ipsos MORI who made the decision to include that question.

The 2009 survey used many of the same questions as the 2008 survey. However, there were some changes. Many of the questions which had proved useful before were removed. For instance, we were no longer able to see how many times people had visited their GP over the previous 12 months. So, while we now had data on people who were deaf and sign language users, the scope of the responses had changed.

Following publication of the results, SignHealth has analysed the figures in detail. The survey once again highlights huge health inequalities. The purpose of this report is to see where the inequalities exist and suggest what may cause them. Our “explanations” are based on anecdotal evidence from Deaf people. Without proper research into the health of Deaf people, this is the best anyone can do.

*“I am a very good lipreader, but I know people have difficulties understanding my voice, so I take a friend with me when I go to the GP. This is a busy surgery and I never seem to see the same doctor twice. Only one of them has ever looked at me when they are answering my questions. They always look at my friend and talk to her and if she asks them to look at me, they forget after a few minutes. I feel like hammering on their desk and screaming ‘I run my own business, I am an intelligent woman; talk to me not her’. Trouble is, I’m too polite.” (Woman, deaf)*

## RESULTS FROM THE 2009 GPPS SURVEY

### WHO'S DEAF?

In 2008 we had to estimate how many deaf respondents were likely to be Deaf with a capital 'D' – that is deaf people who probably lost their hearing at an early age and whose first language is BSL. We were fortunate this time in that there was a direct question: "Are you a deaf person who uses sign language?"

There were 8,212 people who replied "yes" – approximately 0.43% of the total.

Unfortunately, it was difficult to take this figure at face value. Question 44 asked whether the respondent had a long-standing condition, and deafness or severe hearing impairment was one of the options for this. This included deafness due to age and gave a much higher figure (8% of respondents).

We would have expected everyone who said they were "deaf and used sign language" to also say they were "deaf or had a severe hearing impairment". But, of those who said they used sign language, only 39% said they were "deaf or had a severe hearing impairment". It is, of course, impossible to know why this might be. It is likely that some hearing people who can understand BSL chose to complete the survey in BSL – they may have felt compelled to say they were "deaf and used sign language", despite having said they had no "long-standing condition".

What we could be certain of was that people who answered "yes" to both questions were Deaf. There were 2,674 people who answered "yes" to both – 0.13% of all respondents. We used this sub-section of respondents as the basis for most of our analysis.

### SPECIFIC RESPONSES

#### Q12 - If you haven't seen a doctor in the past 6 months, why is that?

89% of all respondents said they had not needed to see a doctor. This compared to only 69% of Deaf people. This suggests that more Deaf people have wanted to see a doctor but have not been able to. The reasons for not seeing a doctor were also revealing. There was far greater distrust or dislike of the doctor among Deaf patients. There was also more difficulty in physically getting to the doctor (10% compared to 2%).

**Why?** Distrust or dislikes probably arise from poor experiences. It may also be more difficult to form a bond with the doctor if communication problems are a barrier. Not easily being able to get to the practice may be the result of additional health problems (as suggested elsewhere in the survey).

### **Q15 - Is there a particular doctor you prefer to see at your GP surgery or health centre?**

As was noted in 2008, trends within primary care are reducing the ability of patients to see a particular doctor of their choice. Results from the 2009 survey support the argument that this is more of an issue for Deaf people than for the general population. Seventy per cent had a clear preference, as opposed to 62% of the general population.

**Why?** We know that if Deaf people establish a system of communication with a doctor then they like to stick to that same doctor. A different doctor will not automatically know how to communicate with the patient – which means the Deaf patient has to explain what works, or muddle through with a system that is worse than normal. Deaf people who rely on lip-reading will normally find it more difficult with a doctor who has a foreign accent or has a beard – this can influence patient preference.

### **Q16 - How often do you see the doctor you prefer to see?**

Linked to the above question, Deaf people are unable to see their preferred doctor as often as other patients. Forty-seven per cent of Deaf people saw their preferred doctor “Always or almost always”, which was 10% lower than for the overall population.

**Why?** There is no obvious explanation for this discrepancy. It is possible that Deaf people are less able to influence which doctor they see. They may not actually book the appointment (someone may do it for them). Some Deaf people may want to avoid the difficulty of explaining they would rather see a different doctor, and may not feel confident about asserting themselves.

### **Q44 - Do you have any of the following long-standing conditions? Please include problems which are due to old age.**

Results from this question reinforce the findings from the last survey. Deaf people are far more likely to have another long-term condition. For instance, 11% of Deaf respondents also had vision problems or were blind – compared to 2% of all respondents. Eighteen per cent of Deaf respondents also said they had a learning disability, a far higher proportion than overall (2%). Similarly, twice as many Deaf people reported having a long-standing psychological or emotional problem (12%). Indeed, only 7% of Deaf people said they had no other long-standing condition, as opposed to 51% of all respondents. This suggests Deaf people have far more health problems than hearing people – and that these problems are chronic.

**Why?** This gets to the heart of the problem. Some Deaf people will have other physical difficulties associated with the cause of their deafness. However, that is not enough to explain the huge differences. It can only be assumed that Deaf people are living less healthy lifestyles because they do not get the same health information as the rest of the population.

Added to that, when there is a health problem they do not get equal access to services (or services do not adapt to the patient's needs). There may also be "overshadowing" where clinicians subconsciously assume that because someone is Deaf other health issues are attributable to that, or more acceptable.

**Q47 - Do you have carer responsibilities for anyone in your household with a long-standing health problem or disability?**

The 2008 survey had shown that Deaf people had more caring responsibilities for people with a disability or long-standing health problem. The results this time were even more dramatic. Among Deaf respondents, 27% had such a responsibility, compared to 9% of the overall population. We know of no other research that has been able to identify this important fact. This figure was high even compared to other sub-groups, such as blind people or the Bangladeshi population.

**Why?** This result was startling. Carers are often a forgotten and overlooked group of people, so perhaps it should not be surprising that a lot of Deaf people are carers. It is impossible to say with any confidence why this might be. It could be that exclusion from the workplace means that – within a family – Deaf people are better placed to be the carer. We know that many Deaf people never leave home and end up being the carer for their parents – often completely hidden from the 'system' and with no support.

**Q31 - In the past 6 months, have you tried to call an out-of-hours GP service when the surgery or health centre was closed?**

Out-of-hours GP care is an important issue for the health service. The results from this question were extremely interesting. Far more Deaf people had tried to contact an out-of-hours service than hearing people (19% compared to 7%).

**Why?** There could be numerous reasons for this. It could be that Deaf people experience ill health more, and therefore need an out-of-hours service more often than hearing people. It could also be because of attitudes to the service, or an inability to see a doctor during normal surgery hours exacerbating a problem.

**Q32 - How easy was it to contact the out-of-hours GP service by telephone?**

Not surprisingly, Deaf people had far more difficulty contacting the out-of-hours service by telephone. What is surprising with questions on telephone access is that some Deaf people are satisfied with telephone access. We know anecdotally that Deaf people adopt strategies that they see as 'normal', but which few hearing people would be happy with, e.g. asking a work colleague to make an appointment, or walking to the surgery. For the out-of-hours service, 37% of Deaf people were not satisfied or had been unable to make contact. This compared to 20% of hearing people.

**Why?** Many Deaf people have adopted strategies for making normal appointments. A huge number will walk to the surgery – something which many hearing people would never consider. However, out-of-hours the situation is more difficult and, potentially, more important. Most out-of-hours services rely on telephone contact, which simply excludes Deaf people. Everyone who needs to contact an out-of-hours service will be anxious and the situation can only be made worse when communication is so difficult. Few out-of-hours services seem to have thought about how a Deaf person can make contact.

#### **Q40 - Which of these best describes what you are doing at present?**

Occupation is a very tangible indicator. There is plenty of research on how employment links to health and wellbeing and the Government is concerned about the economic ‘waste’ of people claiming benefits when they could be working.

Among Deaf respondents, 20% said they were “permanently sick or disabled” (compared to 6% of all responses). Similarly, 10% of Deaf people were unemployed, compared to 4% of hearing people. Half of hearing respondents were in work, compared to just 30% of Deaf respondents.

**Why?** There are so many influences at work, it is impossible to provide one answer. We know Deaf people are often excluded from the workplace – simply because of employers not wanting to employ Deaf people. We also know that some Deaf people experience far poorer health than would be expected and are probably on long-term incapacity benefit. Because employment services find Deaf people more difficult to engage with, there is often not the support to help people find work.

#### **Q43 - In general, would you say your health is? Excellent, Very good, Good, Fair, Poor**

The distribution of responses was interesting. Among Deaf respondents, 12% said “Excellent”, which was 2% more than among the overall population. But, far more Deaf people reported “Fair” or “Poor” health: 32% compared to 21%. This adds further weight to the argument that Deaf people experience poorer health than hearing people.

**Why?** The Deaf population is diverse. While we are certain that more Deaf people experience poorer health than would be expected, this generalisation cannot be applied to all Deaf people. The question is subjective and we imagine that some Deaf people’s assumptions about health are quite different, e.g. they may see poorer health as okay. This would suggest that the ‘true’ results indicate a more concerning situation.

*“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. Yet the Polish lady further down the ward was given an interpreter. This is just so unfair.” (Hearing friend of deaf woman)*

## WHAT IS BEING DONE TO ADDRESS THESE ISSUES?

The Department of Health is working to improve access to GPs and primary care, and the “GP Access Programme” was established because of the GPPS results. There have already been big changes in terms of extended opening hours. SignHealth and other voluntary sector groups have been working to introduce changes for marginalised groups and whilst progress is being made, it is slow. The type of change that is required is a dramatic shift in thinking and attitude rather than simply doing the same thing for longer hours.

If Deaf people lived in specific areas, their needs would become apparent. Because Deaf people can be found throughout the country there are never “enough” for them to be seen as a group. Therefore, systemic changes are less likely to be introduced.

SignHealth has consulted Deaf and other marginalised patients (*Deaf and disabled people's experience of primary care: SignHealth: February 2009*). People were encouraged to say what recommendations they would make to improve access. Five simple recommendations came from this consultation and will soon be promoted by the GP Access Programme. (The full recommendations can be seen in Appendix A.)

- 1 Surgeries allow booking of appointments by text/SMS, internet or e-mail and attention is given to out-of-hours services.
- 2 Staff receive Deaf Awareness, BSL training or wider disability training.
- 3 All patients to be asked how they should be informed that it is their turn to see a doctor or nurse.
- 4 The patient to be asked whether they would like communication support, and if so what kind of support they would like, e.g. face-to-face interpreter, pen-and-paper, online interpreter.
- 5 Patients' notes to clearly state the person's deafness or disability, and any associated adjustments required and preferred communication method — this should be a clear flag on electronic systems.

Changes to access and service delivery are important. However SignHealth remains concerned that health inequality for deaf people is still not being recognised and addressed as it certainly would be for any other minority group.

SignHealth has applied for a second time to the Big Lottery for funding into a major piece of research which will answer many of the questions which up to now are only evidenced anecdotally. SignHealth believes that this research is well overdue and, whilst the charity is prepared to invest in the first stage of the project, it should not be the responsibility of the voluntary sector to commission the study. Until the research is done health service providers will perhaps continue to ignore the needs of deaf people. Commissioners will say there is no evidence. Meanwhile, more Deaf people will suffer unnecessarily and nobody will acknowledge there is a problem within the very system designed to help them.

## DEAF PEOPLE NEED TO DRIVE THE CHANGE

History shows that change rarely comes from the top. Sixty years after the birth of the NHS we still do not have research evidence to show that Deaf people are less healthy. Deaf people still struggle to book appointments and are still denied their right to communicate in BSL.

This is why Deaf people must start to demand a fair service. Asking for an interpreter is not asking for special treatment – it's asking for equal treatment. If a hearing person was faced with a doctor who only signed, you can be sure they would ask for an interpreter: they would demand it.

There are a few simple things Deaf people can do now:

- Register to take part in the research study. Go to [www.iwantbetterhealth.org.uk](http://www.iwantbetterhealth.org.uk) or contact SignHealth.
- If you prefer to use BSL, then ask your GP's receptionist to record your first language as BSL in your medical notes.
- Ask for an interpreter every time you see a doctor — even if there's no chance of you getting one. Tell SignHealth about your experience.
- If you are treated badly then complain. SignHealth can help if you need support.

## CONCLUSIONS

The 2009 GPPS is an important milestone for deaf health. Not only were people asked whether they were deaf, they were also asked whether they used sign language. This is a significant step forward, and suggests that the Department of Health recognises the Deaf community as a distinct group.

The findings show that Deaf people are still being forgotten in practice. There are clear indications that Deaf people experience poorer health and have poorer access to health services than the hearing population. SignHealth is not convinced that future surveys will show any improvement for Deaf people. Frontline health staff need to show a commitment to change at a time of huge upheaval in primary care. With competing demands for resources and attention, SignHealth suspects that Deaf people will continue to be missed.

When the results were published, the media concentrated on the discontent coming from GPs worried that they would not qualify for the payment linked to GPPS results. There were very few reports around the actual patient data.

This is why SignHealth calls on Deaf people to assert their rights and demand change at an individual or local level, thus driving improvements nationally. SignHealth is strategically placed to support this move as well as offering advice and collaboration to healthcare professionals.

## APPENDIX A

*Deaf and disabled people's experience of primary care: What deaf and disabled people would do to improve primary care access.* (A Report published by SignHealth at the request of the Dept of Health GP Access Programme)

### THE FIVE KEY RECOMMENDATIONS

- 1 Surgeries to allow booking of appointments by text/SMS, internet or e-mail; and attention is given to out-of-hours services.

Response after response asked, "Why can't I use e-mail or SMS?" It seems that technological advances have worked against Deaf and disabled people: automated switchboards with options are particularly annoying. We gather from suppliers of patient record software that the capability is already available to a large number of practices. There is also a cost saving involved in introducing electronic booking (EMIS estimate 69p per booking).

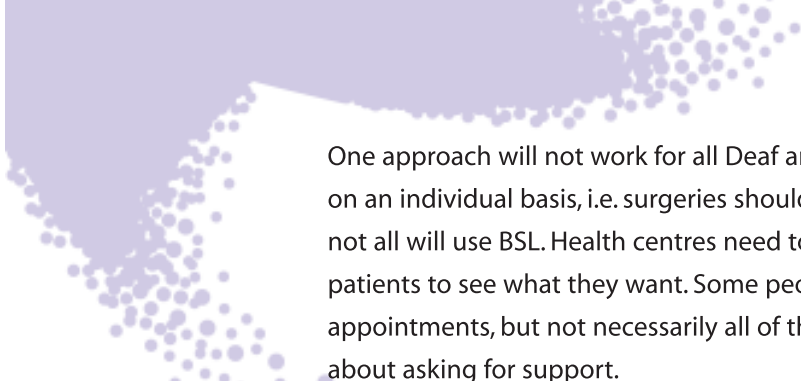
- 2 Healthcare Staff to receive Deaf Awareness, BSL training or wider disability training.

There were numerous reasons given for providing training. Sometimes it was the attitude of staff. Often it was the practical barriers created by ignorance, e.g. glass screens making lipreading impossible, doctors talking to their computer screen, staff assuming written English is okay. In the case of Deaf Awareness there are qualified trainers throughout the country. Many were involved in delivering a programme tailored for health services in 2005.

- 3 All patients to be asked how they should be informed that it is their turn to see a doctor or nurse.

Most respondents had an issue with being called for their appointment. Their proposed solutions differed. Some liked the idea of screens, although these were not always successful as the patient had to sit 'glued' to the screen in case they missed it. Some liked visual 'number' systems. One surgery used pagers, which seemed particularly effective and also worked for those with impaired vision. Systems that relied on the doctor or receptionist sometimes grounded when the people involved changed. Solutions need to be tailored to the individual patient.

- 4 The patient to be asked whether they would like communication support and what kind of support they would like, e.g. face-to-face interpreter, online interpreter, pen-and-paper.



One approach will not work for all Deaf and disabled people. Adjustments need to be made on an individual basis, i.e. surgeries should not book interpreters for all deaf people, because not all will use BSL. Health centres need to be prepared to have a dialogue with their patients to see what they want. Some people said they would like an interpreter for some appointments, but not necessarily all of them. A lot of respondents did not feel confident about asking for support.

- 5 Patients' notes to clearly state the person's deafness or disability, and any associated adjustments required and preferred communication method - this should be a clear flag on electronic systems.

Many people said staff seemed unaware of their deafness or disability. Patient administration systems allow this to be solved and create a system of support: rather than being reliant on staff knowing that Mr Smith is Deaf and needs an interpreter, either face-to-face or online. The interface between the GP practice and secondary care seems to create a lot of problems, with the hospital being unaware that the patient is Deaf or has a disability. If this information is not in the referral letter then it needs to be on patient administration systems. We are told by the developers of computer software that most systems already allow for "auto alerts" to be easily created. Again, this seems to be an example of the potential solution being in place, but not being utilized.

*"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." (Woman – hearing)*

#### **REFERENCES:**

*Deaf and disabled people's experience of primary care: What deaf and disabled people would do to improve primary care access. SignHealth: February 2009*

*Why do you keep missing me? SignHealth: December 2008*



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