



# Deaf Community

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## Stories from the Deaf Community in Stoke-on-Trent & Staffordshire

Revised by Paul Astley - May 2016

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## Glossary -

**DHH** – Deaf or Hard of Hearing

**CCG** – Clinical Commissioning Group

## Introduction

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This report pulls together the experiences of members of the deaf community when accessing health services in Stoke-on-Trent.

It shows that much can be learned from listening to this group when designing services meant to be universally accessible.

## What We Did

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In mid 2015 Healthwatch met with representatives of the deaf community to discuss current issues and concerns, in particular access to services. The comments were recorded and collated into a list of key points.

Nine case studies were also shared with Healthwatch Stoke. These cover a broad variety of themes but all relate to health services.

**Note - Stories are intended to illustrate the kind of scenarios Deaf patients may find themselves encountering and are described by the patients themselves.**

**This study was carried out in mid 2015 and revised to meet a request from Stoke-on-Trent CCG. Some comments may suggest issues that have now been rectified.**

## Recommendations

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1. Engage with DHH to co-produce services;
2. Investigate the further use of technology to support inclusion;
  - Alternatives to phone access to GP appointments could be investigated;
3. Look again at staff training to understand the needs of DHH;
4. DHH could be more easily identifiable on wards in hospital;
5. Work could be done to understand the experiences of DHH in care homes;
6. Work could be done to understand accessibility of counselling service support for DHH in care homes;
7. Particular effort could be made to empower DHH patients to participate in their own care whilst in hospital.

## Talking to the Deaf Community

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In speaking to members of the deaf community, contributors told Healthwatch Stoke-on-Trent that;

- DHH tend not to complain;
- Most DHH cannot read high level English - needs to be plain and simple;
- Access to services that primarily use telephone cause issues around timely support;
  - 'Type talk' is a 24/7 service that enables telephone conversations to take place - 18001 prefix to make calls, 18002 to receive calls;
  - Concerns that technology appears to have not developed at the usual pace for DHH;
- Some GP surgeries support DHH when they are aware that this community forms part of their demographic;
- Services don't seem to know when a DHH is accessing them - there appears to be no flag system;
- Staff training on DHH awareness is in dire need - e.g - mini comm on the wards - staff don't know how to use;

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- The 8am call to GP for app that day is virtually impossible for DHH unless they have carer support - similarly with the out of hours medical service - all operated by telephone;
  - Ward rounds in hospital appear to lack co-ordination when addressing the needs of DHH; for example when communication support is there they seem not to prioritise knowing that the signer is 'on the clock';
  - There's no identification in hospital if the patient is DHH - Compared with the Butterfly logo for Dementia for example;
  - Clear weaknesses in the wide pool of health providers in the city when it comes to staff training;
  - Cuts to the system has impacted on training for DHH - e.g lip reading courses have now been stopped;
  - Issue of Social Care homes where DHH reside, concerns over isolation and affects on confidence;
  - Major issues with counselling service support for the DHH<sup>1</sup>

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<sup>1</sup> PA - more investigation needed.

## Summary of Case Studies (Stories)

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- Staff may be unsure of the needs of DHH patients;
- BSL interpreters not correctly booked and staff seeming unsure how to do it;
- BSL interpreters being inflexible in their attendance (length of time);
- BSL interpreters being booked for too short a period;
- Assumptions that family members and carers will do the interpreting;
- Break downs in communication can lead to patients feeling excluded from their own care;
- Intercoms are not an accessible technology;
- Staff choose to communicate with family and carers over the patient;
- Staff choosing to talk to others rather than next of kin when updating because they are deaf;
- Use of technologies such as SMS or email can help;
- Case studies suggest that clients would like to have interpreters with them for more of the journey;
- Staff misunderstanding an elderly patient as 'grumpy' rather than deaf because they hadn't read his notes;
- Cost can sometimes be a barrier to accessing interpreters.



## Qualitative Data – Stories and Suggestions from the Deaf Community.

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### 1 - Waiting for an Operation

Profoundly deaf and a BSL user - Male aged 34

*I waited some time for a letter from the hospital about my operation as I was expecting to have operation between October 2014 -January 2015. After 6 months of waiting, I visited the hospital and I told them that I have not heard from them. Finally, I got a letter to say that my operation had been booked for February 27<sup>th</sup>. Before the date of the operation, I went to the hospital (with my hearing wife) to have several tests to make sure that I was well enough to have the operation. They asked me questions about my health with the use of a BSL interpreter. They then asked me who will come with me on Friday (the day if the operation). I told them my wife will come with me but she is not an interpreter. The nurse checked if I had an interpreter with me on that day. I told her I didn't, so she said that she would book the BSL interpreter for me. I thanked her and we went home.*

*Then on Friday, my wife and I arrived at the Hospital. The nurse asked us who we were, we explained, and we told her that we expected a BSL interpreter to come for us. Then another nurse asked us the same questions again. I felt that they were confused about the interpreter. My wife and I were unhappy. Later, the doctor and surgeon came to see us. The surgeon informed me that hospital had given me the wrong fasting instructions for the operation. Originally the operation was supposed to take place at 9.30am and it was moved to 1pm, which meant that I had no food for 14 hours. I have diabetes and I was worried about my sugar level dropping. They suggested having a drip and they asked the nurse for one but she said that they were short staffed, and no one could give me a drip. They decided to cancel my operation both because they were short staffed, and also as no interpreter had been booked. I thought it was a waste of time.*

*I went to see my doctor as I felt worse and in pain, and he contacted the hospital. Finally I got a letter for my operation in May 2015. The hospital did book a BSL interpreter this time. On arrival at the hospital, the receptionist's attitude towards my wife and I was bad. They asked us who we were and I reminded her that she is my wife, not the interpreter. We said that we will wait for the interpreter and she said NO! The interpreter was not coming until 8.45am, but we had been asked to arrive at 7am. Finally*

*the interpreter arrived and we all went to the ward. The interpreter told me that s/he was only booked for an hour. I thought s/he should stay with me all the way through from being admitted to the recovery/discharge. The nurse did not know anything about booking an interpreter, and she told us she would not sort out a second interpreter to replace the first one after the hour. She asked the interpreter to find the replacement interpreter. It is not her/his job to find a replacement. The nurse had a bad attitude and we all were unhappy with her. Finally the nurse agreed to phone for the second interpreter. The operation went well, but afterwards they were unsure of what the procedure was with my sick note. There were confused about it.*

**How can this be improved? (Patient thoughts)**

- Right procedure all the way through from admitting to discharge;
- Staff need to show positive attitude towards us;
- Know how to book an interpreter and know how to use them;
- Don't assume wife will do the interpreting;

## **2 - Patient Isolation**

**Deaf Female age 68 BSL user, also uses clear English speech**

*“About 3 years ago I had an operation. I was sleeping a lot for a few days, and then I started to come round. I needed some help and I realised the help/emergency button was at the corner of the room, too far away for me to reach. I tried to shout but the nurse was busy. I kept asking the nurses to move the help button to my bedside but it was always kept in the corner.*

*When the doctor came on the ward round with a group of medical students, s/he would not let me have a BSL interpreter. I don't know what they said to me or the group. I felt so embarrassed. They would not let my daughter in, even though there was no interpreter, to be with me while the doctor was examining and talking to me.*

*Every time I tried to get the staff's attention, they seemed to ignore me or avoid coming to help me. Only one male nurse was very nice; caring and helpful, but he was not there all the time. I was on my own in a big room and I saw no one all morning or all afternoon. Also, I did not like that at night time, a male patient from another room came around to my bed and was tapping at the end of my bed. He was always in a bad mood and I was frightened and did not know why he was doing this. There was no explanation and a lack of security. Nurses would not let me to move to be with other patients.”*

### **How can this be improved? (Patient thoughts)**

- Want to see more nurse/staff involvement with the patients to show care and to reduce isolation;
- Be patient with us;
- Place help button by bedside so that it is accessible.

### **3 - Exclusion and Anxiety**

**Deaf BSL user male aged 55**

*"I was admitted to the hospital for my operation, and during the operation I had to stay awake. A British Sign Language interpreter was with me during the operation so I knew what was going on and what was happening. Then I went to the hospital a second time, but they would not allow the interpreter to go with me during the operation. I was awake and watched the surgeon and nurses talking while they were operating on me. I did not like it as I didn't know what they were talking about and what they were doing; this made me much more anxious. It affected my wellbeing."*

### **4 - Interpreters**

**Deaf BSL User Woman age 65 (illiterate)**

*"About two years ago I was admitted to the new hospital as a day patient for an operation. I had checked in advance whether they had booked an interpreter, and they said yes. I arrived at 7.30 on the day of the operation but I could not see a BSL interpreter. I started to panic and felt angry and then I got more anxious. I had to phone my daughter for help. She was also angry as she had to sort out an interpreter. The operation was postponed and then rescheduled for another date. Then on the day of the rescheduled operation, two BSL interpreters from outside the area turned up. They did not stay with me all day."*

#### **How can this be improved? (Patient thoughts)**

- Staff need to learn sign language to enable them to use basic BSL communication to reduce my anxiety and feelings of panic;
- Want an interpreter with me continuously from being admitted to discharge, as I was on my own all day in an empty ward.

## **5-Communication Barriers**

**Deaf male aged 67 - uses hearing aids and has speech.**

*"I received a letter for my check up. The letter asked me to contact my GP and ask the surgery to book the interpreter. I could not contact them because they only have a voice telephone and message system. There is no email address or SMS mobile number for me to use to contact them. Also they suggested that I ask my partner, or a friend or family member to phone and book the BSL interpreter. Where is my independence and privacy?"*

*I had a bad experience at A & E (Stafford) because my wife died there. She was admitted to A & E as an emergency. I had no interpreter and I had no information about what was wrong with her or what had happened to her. During that time I found it very distressing, and now every time I attend an A & E department, the memory always comes back to me and I find it upsetting. I worry about access to information and communication barriers.*

*I am concerned about experiences at A & E that can affect the wellbeing of people in the deaf community."*

### **How can this be improved? (Patient thoughts)**

- Make contact more accessible such as through email or SMS mobile
- The health provider should book the interpreter for me;
- During an emergency, if the ambulance staff or doctors are aware that the patient is Deaf, they need to contact the hospital to arrange a BSL interpreter to be there for when they arrive at A&E.

## 6 - Patient Participation

**Deaf BSL User Woman aged 56 (illiterate) - No hearing aids.**

*“Last year I was admitted to A&E after the psychological nurse found me collapsed. I was alone at A&E and I did not know what had happened to me. I am not sure if the staff were aware that I am Deaf. When I woke up I told them that I was Deaf. The doctor asked “where are your hearing aids?” and “You need to wear them to hear me”. I was shocked with the doctor’s attitude. I stayed at the hospital all weekend and I had no interpreter. The nurse put a tablet in my mouth and I did not know what it was for.*

*2. I had a health scare last February and was admitted to A&E. I was lying on the trolley for 4- 6 hours alone and I was angry. This has affected my wellbeing and made my health scare worse.”*

### **How can this be improved? (Patient thoughts)**

- Want the hospitals to become responsible for booking an interpreter when I am alone and unconscious;
- Check on me more often and let me know what is happening.

## 7- Carers First?

**Hearing person with deaf parent.**

*“My deaf father had to be admitted to hospital, and the next day when he had recovered, the hospital rang me to let me know that he was ready to go home. When I arrived to collect him, he was not aware that he was going home. Neither the nurse or doctor had informed him. He was surprised when I told him that he was ready for discharge. My father is deaf and human, he should be told first before me. That is his right.”*

## **8 - Exclusion**

### **Deaf couple (BSL users)**

*“My daughter was admitted to the hospital A & E department, and we are her next of kin. Rather than ask us, the nurse and doctor spoke to other people (who were not family members) because they were hearing. We were furious that we were excluded from information about what was happening to her. We brought her up and we know all about her.*

*Access to hospital buildings can be difficult for us as we cannot hear the speaker or speak through the intercom by the door. We have to wait until someone approaches the door from either side of the building. In our experiences, the nurses have showed a negative attitude towards us when we informed her that we had a problem with the intercom. It has happened a few times with different wards”.*

## 9 - Attitudes

### Hearing Daughter of Deaf parent- BSL user male aged 59

*"From 8/8/13 to 20/9/13, my dad only had a BSL interpreter on 3 occasions throughout his stay in hospital, 2 whilst in North Staffs and 1 whilst in Stafford. It was whilst he was at Stafford that we experienced a number of problems with the attitude of staff, and their reluctance to get my dad an interpreter. It seemed that staff were inadequately trained to deal with my father's deafness and resorted to shouting at him and calling him grumpy as he was unable to understand them. This made my dad very uncomfortable, and he would pretend to understand them, for fear of repercussions if he did not. A number of staff also failed to realise that he was deaf as medical notes were not read correctly when he was transferred from North Staffs to Stafford. They also failed to administer the required medication upon arrival at Stafford.*

*When visiting my dad on one occasion, he was very upset that he had not had an interpreter and I approached staff on the ward. I was told that he could not have an interpreter as they were unable to specify a time when the doctor would be visiting the ward.*

*On 12/9/13 my partner's mother visited my father and again approached staff to ask why no interpreter had been made available. She was told very abruptly that interpreters were too expensive and that myself and my brother should act as interpreters, even though we both have full time jobs.*

*My dad's experiences at Stafford Hospital has put a lot of strain on him and my family as these service should be provided and they should not rely on myself and my brother to interpret for staff. I am very angry at the way in which my father had been treated, and the appalling level of care provided by Stafford hospital. I believe staff should be trained better in how to deal with patients with disabilities such as deafness."*