

Report on Access to Health Services for Older Deaf People in England and Wales

Contents

1. Introduction	5
2. Methodology	7
3. Findings	8
4. Narrative and Impact	8
5. Accessing GP Surgeries	9
6. Accessing Hospitals	14
7. Other Health Services	22
8. Geographical Mix	24
9. Gender	24
10. Key Themes	25
11. Recommendations	27
12. Conclusion	28
13. Bibliography	29
Appendix 1: BDA's BSL Charter	30
Appendix 2: Narratives	31
The British Deaf Association – BDA	40

My daughter had to tell her father that he was dying – it is just not fair. (Lady – Letchworth Garden City, Hertfordshire)

[©] British Deaf Association, 2014

1. Introduction

Since the British Deaf Association (BDA) was founded in 1890, its primary purpose has been the status and recognition of the Deaf community and British Sign Language (BSL) in the United Kingdom. The cornerstones of the BDA are:

- Language
- Community
- Identity
- Heritage
- Representation of Deaf¹ people's needs, aspirations, rights and responsibilities.

The BDA is a high profile national Deaf people's organisation with a presence throughout England, Scotland, Wales and Northern Ireland.

As a member-led organisation, our work is focused on achieving equality for Deaf people through community empowerment, membership and campaigning. Working with local Deaf and BSL communities is crucial to the success of BDA campaigns and creates opportunities for Deaf people to develop, participate and contribute in wider society.

The Community Empowerment Team (CET) was established in April 2012. This is the public face of the BDA working at a local operational level and the link between local Deaf communities and the national campaign work of the BDA.

The team's objectives are to research, identify and meet local Deaf communities to establish and – in some cases – re-establish links between the local communities and public services.

Positive progress has been made by increasing the number of contacts and building upon known existing links with the many varied Deaf communities across the regions. This was achieved by instigating a series of successful visits and presentations during the first two years of CET work.

A notable feature of this work has been the promotion of the BDA's BSL Charter. This sets out five pledges to ensure local authorities meet their legal obligations under the Equality Act 2010.

During this time, it became evident there were challenges in reaching the older Deaf communities across England. However, the existence of the popular England Deaf Darby and Joan (EDDJ) annual holiday rally for over 55s seemed to be an ideal opportunity to gather some qualitative evidence.

Consequently, in October 2012, in our role as BDA Empowerment and Campaigns Officers², we joined the EDDJ in Skegness for two days to assess whether or not it would be possible to carry out a survey the following year. It was also an opportunity to build up relations and trust with those at the rally as many of those attending are repeat attendees. We felt it was important to appreciate that older Deaf people are wary of people they do not know.

¹ The BDA uses a capitalised 'D' to denote those who use British Sign Language and consider themselves as part of a Deaf community with its own language and culture. A lowercase 'd' is used to describe those who have hearing loss and are not seen as members of the Deaf community.

² Robin Ash & James Mclean

The following year the EDDJ rally took place at Butlins, Minehead, Somerset from 30 September to 4 October 2013. We attended for a whole week to enable us to have access to and survey a proportion of 850 Deaf people in attendance from all over the UK. The aim was to obtain the experiences and impact of accessing health services in their own local areas.

This report outlines the methodology used, findings, key themes and recommendations.

2. Methodology

After visiting the EDDJ rally in Skegness, we took a decision to take a week in Minehead for the purposes of interviewing people face-to-face. This decision was influenced by evidence indicating that the older generation of Deaf BSL users have had limited access to education, consequently literacy skills are much lower compared to that of the general population. In addition, many older deaf people have limited or no access to social media. Historically they do not respond in an open and frank way if sent written forms to complete. To source so many people within this age category across the country would have been a monumental task and to follow up with face-to-face interviews would have been equally challenging.

For us to be able to access those older Deaf people who prefer to express their views in BSL enabling to contribute their own ideas and solutions in a culturally safe environment, the EDDJ rally in Minehead was an ideal event to meet those requirements.

2.1 CONDUCTING INTERVIEWS

Both of us spent significant amounts of time talking in BSL with attendees in various locations at different times of the day during that week. Interviews took place either individually, or in groups of no more than six, depending on individual preferences.

The aim was to ascertain if they had issues in accessing local council services. Additional questions were asked about how they felt they had been treated and what could be done to improve their individual experiences. There was also opportunity to discuss what support was available to resolve whatever issues arose as well as the overall effect it has on their lives.

Limited research has been undertaken regarding accessing council services, but even less on how older Deaf people feel about the way they have been treated and the isolation they may experience accessing council services. Older Deaf people have had very limited opportunities to share their experiences of accessing council services in their preferred language, BSL.

2.2 OUR APPROACH

We wanted to understand how older Deaf people perceive health service provision and what they view as health services. Do they understand their GP, the literature they are given, how to safely take their prescribed medication, their diagnosis, lifestyle choices, group therapy sessions, understanding treatment programme plans, different diseases/illnesses and the effects on their health?

If not, how do they access this information? How do health services become more accessible for this group of people?

3. Findings

3.1 THE INTERVIEWEES

From the group of 850 people in attendance, approximately a quarter was interviewed (200 in total).

We were also mindful of the fact that the EDDJ was their annual opportunity of meeting and socialising with their friends from far and wide and perhaps their only holiday. Many stayed the week at Butlins and many took the opportunity to visit the local area and sights. We would not be able to interview everyone but we managed a high rate of return.

One impact of undertaking this survey was witnessing first-hand the emotional outpouring from interviewees when revealing their experiences of accessing council services.

This was offset by how readily interviewees also wanted to share their positive experiences as well.

4. Narratives and Impact

4.1 TRANSCRIPTS

The transcripts were recorded using sign language interpreters who voiced into a recording machine. This was then typed up into comparable English. As BSL is a different language with a distinct grammar and syntax, it is inevitable that some of the English lacks coherence or strict grammatical rules but this is counterbalanced by its accuracy. Wherever possible we have added notes to clarify what the person meant. The following is a sample of what was said to us and we have grouped these into three categories with the rest in the appendix:

- 1. Accessing GP Surgeries
- 2. Accessing Hospitals
- 3. Other Health Services.

5. Accessing GP Surgeries

There were three main areas of concern. These are: reception areas and how Deaf people are informed; communication with GPs; and suitability of interpreters. We have also highlighted instances of good practice.

This is surprising as previous work by the BDA has shown that a main concern has been booking appointments as well as the above issues. Respondents however have focused mainly on communicating with GPs and ensuring that there is accurate diagnosis leading to clear information about the condition and medication. There were some examples of good practice but generally, poor practice prevailed.

RECEPTION AREAS

For many Deaf people, this is an area of concern because many receptionists do not use BSL, and there are no visual display indicators to alert people to their appointments.

I hate my GP waiting room, as there is no display to tell me when my time is and the receptionist walks in shouting my name.

(Gentleman – Harrow)

I have problems with the receptionist calling my name, she has walked around the waiting room shouting it and holding a paper with my name in big letters.

(Lady – Kent)

The waiting room does not have a name display so the receptionist shouts my name several times which is embarrassing.

(Lady – Kent)

With some forethought, some of this could be avoided. There are Visual Display Units used in some surgeries. For older surgeries, a simple way of avoiding difficulties or embarrassment is to either alert the Deaf person visually or by direct contact.

Receptionists all know me – the GP himself comes out and fetches me when my appointment is due. He never gets the receptionist to shout me.

(Lady – Sutton Coalfield)

The GP always comes and tells me when he is ready for me. (Lady – Birmingham)

COMMUNICATING WITH GPS

This was an area of concern that provoked many responses. Most centred on the importance of communication. Some GPs do not appear to appreciate the issues for Deaf people.

When I visit my GP I have to communicate using written English, which is very difficult for me as my first language is BSL. (Lady – Kent)

When I visit my GP there is never any interpreter been booked and I have to converse via

written English, I would feel more confident if there was an interpreter booked.

Under confident with speaking to the GP with written English. (Lady – Essex)

At the GPs we get no interpreters – the hospital support is lovely. The GPs just don't understand. I asked the GP for an interpreter and was told they no interpreters! I told them they are wrong – they say no time to sort it out and the doctor does not sign.

I feel I don't understand and I feel unwanted. (Lady – Worksop)

A major concern was the lack of interpreters. The following transcripts clearly indicate the struggles that respondents had in asking for interpreters.

At the surgery, the interpreter did not turn up and when I asked the GP he said you should bring your own interpreter! Then he told me to phone for an interpreter – I said "How can I phone? I am Deaf" – I just put my hand up and walked away.

I do not like interpreters from out of the area – I don't know them or understand the signs that they use I prefer CU (Communication Unlimited)* – I just don't trust interpreters from out of the area. I ask for their badges, I want proof that they are qualified – some err and um and can't show me their badges.

I didn't like his attitude and it made me feel very upset and made me feel quite annoyed and very angry. I felt like I wanted to punch him so I walked away and tried to calm down – my wife told me to calm down.

(Gentleman – Derby)

* Interpreting agency

I always have an interpreter for hospital appointments but with the GP I go on my own. If I want to see the GP tomorrow I know they can't get an interpreter for tomorrow so if I want an interpreter I have to wait for an appointment so I tend to go on my own.

(Gentleman – Liverpool)

It is dangerous for Deaf People that GPs not book them. When they are giving us in depth information and using words about health that we don't know or understand.

It is important to have interpreters especially if they are talking about tablets and medication – we need the full explanation. I don't want to miss any information or service.

If I have an interpreter I feel lovely. When the interpreter is there it is just lovely. They arrive early and I feel comfortable while I am waiting to see the GP.

Sometimes it is not appropriate for my daughter to be there – some things are private – I didn't want her upset or start to cry.

(Gentleman – Tameside, Manchester)

It is very difficult in the GPs and I get very frustrated. This October they finally booked me an interpreter to support me, only had interpreter once – it was the 1st time ever.

```
It makes me feel fed up. (Lady – Chester)
```

When I attend a GP appointment I usually communicate via written English but recently had an interpreter, which was great as it made things much similar*.

(Lady – Wigan)

* simpler

I have a problem with my diet and they talk about me not to me – when they talk to me they say simple information even with an interpreter – it is difficult – why don't they give me the full information, it is hard.

I told the GP if there is no interpreter there I will walk out. So they have to move the appointment which is wrong and not fair. (Lady – Islington)

There are very few interpreters which means that we rarely get one offered at appointments. The GPs are reluctant to pay for this support and say that we can manage via written English. On rare occasions that they have provided an interpreter then someone has been booked who does not hold a NRCPD* registration and low level qualification.

I feel like giving up asking for appropriate communication support. (Lady – Grimsby)

* Unqualified and not registered with the National Registers of Communication Professionals Working with Deaf and Deafblind People (NRCPD)

Many people use relatives. For some, this was a mixed blessing as this meant that they thought they got full information but they did not always want the relative to know. It must also be borne in mind that relatives are often not trained in interpreting and may have their own difficulties.

I have a new GP – I go with my sister who interprets for me. The hospital always provides interpreters but not the GPs. If the GP sends me to the hospital they phone my sister – why do they phone her and not write to me!

(Gentleman – Loughborough)

I never ask for an interpreter as they always say they have no time! I use my daughter if I go to the GPs etc. It is much easier if I take her with me. I am more comfortable with my daughter – I understand what she says. My daughter knows all about my health problems and me and I don't want to tell someone I don't know about it.

I am worried about the future and how we get support. It's sad really – we do need more interpreters.

(Lady – Chester)

My daughter comes with me for GP appointments etc. – I can communicate with them myself but I can see there are a lot of problems for other Deaf people who can't. There is a real lack of services for Deaf people.

(Lady – Norfolk)

My daughter helps me interpret at the GPs – I want this to be private, I don't want my daughter to know as I don't want her to panic – or my son.

(Lady – Wisbech)

This is from a hearing relative.

I think that when we go to the GP and places like that it is quite embarrassing for me to have to interpret some of the medical things she needs to know. An interpreter is a separate person; they don't listen to what is being said they just interpret that information.

(Hearing Husband of a Deaf Wife – Alton, Hampshire)

SUITABILITY OF INTERPRETERS

There are also concerns that interpreters are not always the answer. They need to be appropriate for the Deaf person. There are also concerns about clarity of the signs used, and also the code of ethics.

I live in a small village – there is only my husband and me who are Deaf. We get no access to interpreters for GPs and I am diabetic. If I had to go to the hospital I would be worried as I don't know who the interpreters are!

(Lady – Oakleigh, Liverpool)

My GP has said that rather than book interpreters then if he writes simply and make sure that I understand then there is no need to book interpreters. I think that he will not pay for interpreters because they are too expensive. I am happy not to have interpreters at my appointment because I do not trust them, as they will tell everyone what is wrong with me.

Suspicious of the interpreters as they break confidentiality. (Lady – Wrexham)

I have to communicate via written English with my GP, I have asked for interpreters but the GP said "Why" They eventually provided interpreters but appointments are delayed, by which time my health has improved. The interpreters booked have been female and this is embarrassing, as I have needed to undress in front of them.

I feel that we are being ignored when asking for better access. I feel very uncomfortable about the gender of interpreters that health provides as I need a male and one who is not homosexual.

(Gentleman – Enfield)

GOOD PRACTICE

There is some good practice where the needs are being met. The following illustrate that it can be achieved.

The GP knows me and it's the same with the hospital – they always provide interpreters even when I have had to have an operation.

(Lady – Birmingham)

The GP always phones and the interpreters are always there. The GP won't talk to me unless the interpreter is there which is very good.

(Gentleman – Liverpool)

If I have an appointment for the GP they book an interpreter for the time – that is good. (Lady – Bridgewater, Somerset)

There are no problems – my GP knows me well and we use pen and paper to communicate. (Gentleman – Coventry)

These transcripts show that good communication is paramount. The following transcript shows what happens if this is not the case:

Communication at the GP is appalling. I had a stroke 7 years ago and a priest turned up at the bedside – I thought he was there to give me the 'Last Rites' – I didn't understand why he was there and it made me really frightened – no interpreter support.

(Gentleman – Surrey)

6. Accessing Hospitals

Access for Deaf people is required with the following:

- Visiting reception areas
- Communicating with doctors
- Operations
- Post-treatment care
- Accident and emergency situations.

The following transcripts focused mainly on the experience of attending hospital or being in hospital. Not surprisingly, many responses centred on the lack of interpreters, although some hospitals do provide this service. The main areas of concern covered communicating with doctors, provision of interpreters, suitability of interpreters and communication generally. There are also instances of good practice.

COMMUNICATING WITH DOCTORS

If I needed to see the doctor I would go and make my appointment first and then tell them please I need an interpreter to be provided so I can explain to the doctor what was wrong with me. The 3 way conversation is much better and the interpreter was there. At work I had a pain in my tummy and was sent to hospital — no interpreter provided and it was very hard to make them understand what was wrong with me.

When in hospital without interpreter it was very difficult trying to write notes to explain how I was feeling and what was wrong with me when I was in so much pain.

I was quite scared and apprehensive, as I did not have the full information about my condition and how it was caused.

(Gentleman – Bedford)

When we go to the hospital there is no interpreters – they never turn up. My friend went to hospital – he is diabetic. He knew nothing about diabetes as he was newly diagnosed. He needed to know what was going on and how it affects his health.

I feel really fed up with this and upset. It makes me angry and it is not right. I feel so angry – it is important for Deaf people to have access to the information.

(Lady – Oldham)

My 3 children are all Deaf as are my mother and father and all this information is on our medical records. We must have interpreters for doctor's appointments but they don't provide this for my children – they always do for me! I don't always get an interpreter at the hospital.

My daughter was rushed to A&E and was sent to a ward – she is only 15 and Deaf – they wanted her to write down on paper to communicate – she had loads of bits of paper. She did have a serious condition but we didn't understand and eventually a doctor brought an interpreter to assist and then my daughter could really tell them what was going on and ask questions.

They know I am Deaf and it makes me very frustrated. All this writing notes is no good. (Lady – Cambridge)

When my husband was first rushed to hospital on the first day he was fine, on the 2nd day he was much worse and was on oxygen (the nose pipes), on the 3rd day he was on a full face oxygen mask – at 2.45 he shut his eyes for a sleep so I went to work, when I came back he was in intensive care and had to go for an operation. I saw a poster there about interpreters, minicoms* and access – I went everyday but the communication was horrendous.

I was completely out of it. I didn't know what was going on – they kept giving me papers and the English that it was written in I couldn't understand.

I am angry. Very, very angry – I will never forgive them, never forgive them.

As a Deaf person without the communication or access to the information was awful. (Lady – Nottingham)

* Textphone

My husband has health problems and it is difficult to get hospital appointments, as there are no interpreters. We are constantly fighting. He has to go to the hospital regularly and they never book an interpreter. They say use pen and paper. I can't do that it is very frustrating. We have been like this for 7 years now.

I feel frustrated, I have lost my confidence. I am exhausted always seem to be fighting for him and it is very stressful for me. I just want them to be aware that Deaf people need the interpretation – Deaf people need the information about their health conditions. (Lady – Essex)

I was in hospital — I had a heart attack. I was rushed in and the nurses and doctors were all around the bed. I was nervous — they were all talking and I didn't know what they were saying — I didn't understand a word. I said I need an interpreter straight away — they said they couldn't do that! I couldn't ask them to write anything down — they use big words and I don't understand the doctors writing, as it is very poor — I just didn't understand.

It makes me feel fed up – we have to suffer the pain. There are no interpreters and we need to complain.

(Gentleman – Caerphilly, Wales)

PROVISION OF INTERPRETERS

One key point is the variable service. This is an example of how some services provide an interpreter but not others:

I have breathing problems and I can't fight anymore – I can't explain how I feel – my wife does things for me. When I over exert myself, I get short of breath and it makes my condition worse.

I am not happy – I feel fed up. Health is important – people's health is really important. I have diabetes and every 6 weeks I get an interpreter for my chiropodist appointment – every 6 weeks for a 5 minute appointment but when it comes to my lungs I get no interpreter at the hospital. (Gentleman – Essex)

Part of the reason for the variable service is that different services book interpreters through different agencies. This makes it confusing.

We have Manchester and Greater Manchester and local hospitals. I am sick of going to one hospital to be told that the contract for a particular thing is held with the other agency. My condition means I have to go to different hospitals for different treatments but each of the hospitals have different contracts with different interpreting agencies — so this means I don't know which agency is which and then how do I make a complaint — it could be the same interpreter and they could work for 4 or 5 or 6 different agencies so it is very difficult to make a complaint. (Gentleman — South Manchester)

I couldn't go to my local hospital as I had to go in as an emergency — I asked do you have an interpreter. I thought I need an interpreter — I couldn't communicate via pen and paper. They said there would be an interpreter but only for 1 hour. That was all I needed. Every morning when the doctor came round the interpreter was there — lovely. I then had to be transferred to another hospital. When I arrived at the other hospital there was no interpreter. I was so frustrated. I went mad with them — I refused to do anything they said and they thought I had a bad attitude, if I was a foreigner they would have brought an interpreter in for me! I refused treatment until they brought an interpreter for me — eventually I got one. (Gentleman — Islington)

A major issue is the timing of booking interpreters. An example would be that interpreters are booked for the operation itself but are not available for the post-operative care. Another is that interpreters are only booked for specific times.

When I had an operation there was an interpreter there when I went in then they left and for the rest of the time I was there I had no interpreter. I had to communicate by writing notes — the words were too long and I didn't understand what they said as my English is not very good. I'm not clever like that — I have not been to university or anything like that — I don't have a degree — I don't understand written English like that. I wanted to know what these notes meant so I had to ask my sister what they said.

(Gentleman – Swindon)

They provided an interpreter for my wife when she had a hysterectomy but the next day there was no interpreter for the post-operative information. There should be an interpreter there daily for the consultation meetings with the doctor.

I am really disappointed. It is such a waste of time. (Gentleman – Swindon)

In January I broke my wrist — I had an interpreter there but that interpreter had to leave as they said they were only booked for 2 hours. My husband was with me but he is Deaf. The doctor said if interpreter has gone you have to go home! The planned operation could not take place without the interpreter! I think this was awful — the doctor said if interpreter goes they will cancel again.

I was really mad when they cancelled the first one – everyone was looking at me. (Lady – Bradford)

SUITABILITY OF INTERPRETERS

Respondents also reported on the suitability of interpreters particularly when it comes to intimate matters.

If an interpreter turns up and I am going for treatment for my prostate cancer – obviously I have to get undressed and if it is a woman interpreter that is not appropriate. What do I do then? Why have they sent a woman?

(Gentleman – South Manchester)

When my husband was diagnosed with prostrate cancer we were actually away and our neighbour had the keys and we had asked him to check our mail and text us any news. He texted us with the news and the appointment time so we asked him to contact them and make sure that an interpreter was booked. They were going to send a woman and we disagreed and asked for a man, as this was more appropriate.

(Lady – Welling, Kent)

There are problems – I went to hospital in emergency and they got me a male interpreter – I want a female one and had to wait for 7 hours for one to come. A male interpreter is totally wrong for the situation. We should have interpreters at the hospital – they brought one that was level 3 not a qualified interpreter.

I was upset and crying, it was an emergency and I needed a woman interpreter – I feel like they ignored me. I am Deaf and disabled too. If I fall over in an emergency whom do I ring? The police – 999 – would they break in to my house – who do we ring? (Lady – Manchester)

When interpreters are not booked, family members often find themselves in situations where they need to interpret. For some, this is a familiar occurrence, while for others it can be a stressful experience.

If I have any appointments with the doctor or hospital I always take my daughter along with me as interpreter. I prefer to use my daughter, as it is so easier and quicker. Before my daughter improved her signing then I had to use interpreters and I felt so frustrated with the wait or having to see the doctor using written English.

I feel unhappy about waiting a long time for the hospitals or doctor to book an interpreter. (Lady – Wolverhampton)

My daughter lives in Nottingham and she visited with her Grandfather and he had to go into hospital. She had to support her Grandfather and us as while he was in hospital. We wanted a proper interpreter to access the information now! It is not her responsibility. They should have provided an interpreter.

Very fed up and feel that they should have provided an interpreter straight away. (Lady – Hampshire)

I went to the GP with a problem with my throat – they said go to hospital but didn't tell me why – they just wrote a letter. I asked for an interpreter but in the end my daughter had to come with me. They told me to sit down – a surgeon came in and stuck a camera down my throat – I was shocked and said 'whoa' – what's happening! – There was no explanation – nothing – it made me jump. When the camera came out the surgeon said OK there is nothing to worry about you haven't got cancer. I was completely dumbfounded! My daughter burst into tears.

It is not fair on my daughter to go through that experience. After this I don't have my daughter to interpret for me – it is not fair and causes additional stress for her. It is just not fair.

When I phone I get no reply – I just can't believe it and I feel really let down to be fair. (Gentleman – Sandwell)

Father went to hospital – communication broke down completely. My niece who is only 15 years old was there – when the ambulance arrived there were no interpreters so used my niece – wrong really. My dad had tests and had to go to different departments and my niece asked please can you get an interpreter – they kept saying 'wait, wait a minute' and if I asked they said the same. They told my niece that there was no interpreter available – so we waited until 5am.

I felt very nervous – my confidence went. My niece got upset and when she got home she burst into tears – she was very upset as her granddad in hospital – she is not an interpreter, she is still at school and it's not fair to put her in that position.

(Lady – Leicester)

It was awful without an interpreter – for hearing people it is easy. Deaf people get no information – how do we know what signs to look for in the first place to know that something is wrong with us. My daughter had to tell her father that he was dying – it is just not fair. (Lady – Letchworth Garden City, Hertfordshire)

A common complaint was that interpreters don't turn up. The BDA's experience is that this is often because they have not been booked in the first place. The experience of respondents is that they arrive but there is no interpreter.

I got a letter to say I had an appointment and an interpreter had been booked. When I got to the reception she picked up the phone to ring for an interpreter – how stupid – why put it on my letter if they hadn't done it.

I lost my temper, I got very angry, my wife wouldn't let me go in without an interpreter. (Gentleman – Huddersfield)

Sometimes when I turn up to my appointment and the interpreter does not turn up it makes me frustrated. I went for an operation on my eye and the interpreter had not arrived so they said I had to book another appointment for another time.

When I was told that it had been cancelled again – it made me so depressed, no interpreter and the reception kept trying to reassure me but it was making me frustrated. I just felt that they were wasting my time and I was so very annoyed and made me feel very down. Not happy at all. Makes me really disappointed.

(Lady – Birmingham)

I had been booked for an eye operation, arrived at the hospital and waited for the interpreter to arrive but never did. I had to go through the whole procedure without communication support. (Lady – Stafford)

The hospitals and GP never book interpreters to any of my appointments. I see that the Asian communities always have interpreters but BSL interpreters never turn up or they are simply not booked.

(Lady – Tipton)

I have been let down by interpreters at times and sometimes they have been there.

I manage by lip reading when the interpreters don't turn up – not perfect I just manage. (Lady – Birmingham)

COMMUNICATION

Some complaints are more about communication. This is something that could easily be resolved with some training and political will.

The hearing aid clinic is the worst ever – I write down that I am Deaf – they close the door and then shout my name from the other side of the door – all of us there are Deaf – no staff can sign in the hearing aid clinic – COME ON...
(Lady – Wales)

I was on morphine so couldn't see what she was trying to say – I couldn't communicate with her – I didn't know what she was saying. I broke down and cried.

As a man – this made me feel really awful – total breakdown in communication. (Gentleman – Oldham)

After an operation I had I told the nurse that I was Deaf and needed an interpreter for my husband as well. 20 minutes later the nurse came back and started talking to my husband. I said he is Deaf! Then a doctor came and started talking and I had to say again I am DEAF!

They ignored me! (Lady – Oldham)

Nurses can't communicate with Deaf People. They should have basic easy signs to ensure Deaf people have access such as toilet, drink of water, directions and things like that.

I know in Ireland that the nurses studying learn ISL* as part of their training. This started about 12 years ago and it has really improved services so much.

(Gentleman – South Wales, previously from Birmingham)

* Irish Sign Language

I had to go for a camera up my nose and down my throat — I asked them to book an interpreter and when I arrived at reception I was told the interpreters were too busy. I said I couldn't hear if you shout my name I am Deaf. I sat facing reception and asked when it was my turn if they could wave at me. So I sat and sat and sat. Then I looked at my watch and realised my appointment should have been half an hour ago — still waited patiently. I looked at my watch and now it was an hour late. She said she had forgotten about me. I then thought I really should have an interpreter here, as the doctor was black and I really can't lipread foreign people's lips — they have wide lips and small lip shapes. I am not being racist here!

I said don't touch me as I don't know what you are on about! I started to panic, I thought they would force me to have this done; I started to cry and panic. The doctor looked at me like I was stupid but I had no access to the information. Eventually they did the procedure and afterwards I was so upset and crying – they sent me away and I didn't know if I needed to go back or anything. I had no information given to me. (Lady – Norfolk)

GOOD PRACTICE

Many of these instances could be avoided with some planning, appropriate budget allocation and clear policy guidelines. The following transcripts show satisfaction when hospitals "get it right."

UCH hospital is where I go – it is a famous hospital. It is very good and always provides interpreters. It is very good in Islington. (Gentleman – London)

We get interpreters for health and support for hospital appointments. It is really good – fine as we have interpreters provided.

(Lady – Worcester)

I had a major operation about 5 years ago – PALS were very good, they provided an interpreter every day while I was in hospital – it was fantastic.

(Lady – Wandsworth)

There are no problems at the hospital – if I ask for an interpreter they book one – no problems – lovely service and I value that as I am getting older and need more information as we get more unhealthy.

(Lady – Swindon)

At the hospital at Barnsley the interpreters are very good. They are always booked; they always come and are very good.

(Gentleman – Barnsley)

I've have an operation and they did provide interpreters otherwise I would not understand what was happening to me.

Interpreters there made me feel much better as with hearing people they always understand what is being said and to have the interpreter there they tell me what is being said which makes me feel much better.

(Lady – Bedford)

We have no problems - the support is excellent – they always provide an interpreter every time. There is no problem as when they see it is a Deaf person they book an interpreter straight away. The PALs service support us.

(Lady – Barnsley)

7. Other Health Services

The following transcripts cover:

- Dentists
- Opticians
- Paramedic service.

There are various issues. Some cover the reception area, while others are more about communication or interpreters.

I told them I was Deaf and they told me to wait and they would let me know when it was our turn. We waited such a long time – a man came and kept shouting the same name over and over and luckily a woman sat in the waiting room saw us signing and asked us if it was our name they were shouting – I could have been sat there all day!

We wait such a long time and I mean they have televisions there for patients to watch but no subtitles for the Deaf. If they had subtitles on the TV then we could watch it also. Often there are no interpreters present for our appointments. (Lady – Walsall)

If I go to the GP or Dentist they know I am Deaf but they still shout my name when it is my turn – they just don't bother. Sometimes a hearing person next to me and they ask me my name and tell me they are shouting me.

It is embarrassing and frustrating. (Lady – Birmingham)

For example I was at the hospital Dentist. I was waiting and waiting and the waiting room emptied until it was just me left waiting. I was supposed to have a tooth pulled out. I went to the desk and they said Oh we have finished – we shouted your name earlier!! They managed to fit me in at the end but I had sat there all day for nothing.

(Lady – Nottingham)

Sometimes they tap me on the shoulder and indicate that I should follow them so I do and I feel like a little puppy dog following them this way!

(Lady – Hinckley)

The following transcripts concern poor communication.

My father fell at home. He had Care Call. An ambulance came and I got a text telling me. I went to his house and was trying to explain that I am Deaf and that my dad was Deaf too. When I arrived a lady from across the road came over so the ambulance crew talked to her and not to me! I felt like hold on a minute I am the son here, its my father — talk to me! Then my daughter arrived and so they spoke to her and not to me — they should have talked to me! (Gentleman — Leicester)

I went to see the nurse and she was a Muslim with a face veil – I couldn't see her lips. (Lady – Blackheath)

I had a bad experience with a Dentist – we told them that I needed an interpreter for my appointment and the Dentist didn't like this. Then they told me the interpreter couldn't make the appointment and refused to change my appointment. When I arrived I told the receptionist I was Deaf but she still shouted my name out! I asked for some paper to write notes and the treatment I received was really patronising. He put the mask over his face but I could see it moving and I knew he was talking to me but I couldn't lipread him. After they gave me a piece of paper to say I had to go to the hospital as they were referring me but I didn't know what for!

Their attitude was very bad and patronising. The reception desk is high and I am small – I asked for some paper to write them a note and I could see them talking to someone else and I knew they were talking about me! I was very annoyed.

(Lady – Norfolk)

I went to the dentist and had no interpreter, as I couldn't understand them and was unable to tell them which tooth was hurting they extracted the wrong tooth!

I am scared for life with the dentist; if they booked an interpreter then this would not have happened to me. It was a very painful experience. (Lady – Smethwick)

The next few transcripts concern interpreters – or rather the lack of availability of interpreters.

I don't get interpreters for the Dentist – that service has stopped now. They said it was because it was difficult for the interpreter to be in the room at the same time and it is difficult for the Deaf person to see the interpreter and confusing for the Dentist.

It is difficult now they have stopped the interpreters for the dentist. (Gentleman – Barnsley)

I was very frightened to go to the Dentist so I asked for an interpreter – they said I couldn't have one as all the interpreters were busy and can't make the appointment. (Lady – Nottingham)

When I went to the dentist they said the NHS has no money to pay for interpreters. I managed to get by with notes. (Lady – Richmond)

Suitability of interpreters has been a recurring theme in this survey as evidenced by the next comment.

I had an optician's appointment and a male interpreter was booked, he was very controlling and took over the appointment. I was very angry because he misinterpreted a sign for Epilepsy when he should have voiced Diabetes. That worried me very much. (Gentleman – Reading)

8. Geographical Mix

On completion of the interviews, respondents were identified as coming from the following regions:

Region	Percentage
North West	16.8
North East	5.0
West Midlands	16.8
East Midlands	10.4
East of England	8.4
South West	14.3
South East	7.1
London	13.6
Wales	7.1

9. Gender

The following is in the gender breakdown:

Gender	Percentage
Female	62
Male	38

10. Key Themes

To summarise the multiple experiences of local Deaf patients in various parts of the country, the following are some of the key themes:

10.1 BOOKING SYSTEM

Respondents repeatedly cited frustration with the system and the difficulties of being accepted as a Deaf person who requires a sign language interpreter. There is also a lack of communication between GPs, Accident & Emergency departments, the ambulance service and hospitals. The outcome is that Deaf patients keep having to repeat the information that they are Deaf and require a sign language interpreter for every single booking and often this information is not acted on or kept for future reference. The recent research by SignHealth: "Sick of It" found that while 8% of the general population found receptionists unhelpful, the percentage of Deaf people with the same opinion was 40%.

10.2 RECEPTION / WAITING ROOMS

Systems which rely on voice announcements often lead to receptionists shouting names out. When there is a failure to respond, receptionists often have to take more direct action such as entering the waiting room which causes embarrassment and draws unwanted and unwelcome attention to them. Other waiting patients are left wondering why the Deaf patient did not respond and this often has the effect of making the Deaf person feel stupid. On occasion appointments are missed because Deaf patients did not hear their name being called out. This adds stress – the experience of waiting is disrupted by the need to watch out for anyone calling out names or of other patients moving out of the room. Installing visual display units in addition to voice announcements would be a fairer and more equitable system, and would lead to a reduction of time being wasted and missed appointments.

10.3 MEDICAL JARGON

Respondents reported that they frequently did not understand medical terminology and this led to the fear of not understanding what medication they are required to take. Written information is often not understood or understood imperfectly. This causes anxiety and the refusal to provide interpreters to clarify the information leads to more avoidable worrying and stress. The SignHealth: "Sick of It" research stated that: "Deaf people who have been told they have high blood pressure are three times more likely than everyone else to still not have it under control – 62% compared to 20% generally."

10.4 INTERPRETERS

The widespread experience of the lack of interpreter provision all over the UK causes deep concern for the majority of Deaf patients. Requests are repeatedly ignored but when responded to it is often with inappropriate or unqualified interpreters. There were also instances of interpreters refusing to show their National Register of Communication Professionals for Deaf People (NRCPD) badges to prove they are registered and qualified and therefore safer. The lack of knowledge about interpreters by GP surgery staff and hospital staff also meant that there was an assumption that sign language interpreters could be booked at the last minute, which in reality is virtually impossible.

The use of family and friends is sometimes a preference by some respondents but for others it is resource that they would not rather use. The continued failure to provide interpreters leads to mistreatment and miscommunication. In addition, "The Sick of It" report stated: "70% of Deaf people who haven't been to the GP recently wanted to but didn't go mainly because there was no interpreter." This was not a question asked of respondents as we concentrated on their actual experiences, but it is probable that the continuing difficulty of understanding GPs or doctors at the hospital led to many avoid going.

11. Recommendations

- 1. All NHS Trusts and GP surgeries to comply with the Equality Act 2010 by developing appropriate policies and establishing good practice in order to provide "reasonable adjustment" for Deaf people
- 2. All NHS Trusts to sign up to the BDA's 'BSL Charter'⁴ as part of good practice on improving access to health services for the local Deaf patients and to use the BDA's 'Checklists for Health Boards and NHS Trusts'⁵
- **3.** As part of developing good practice, all NHS Trusts and GP surgeries to ensure that receptionists, nurses and GPs undertake bespoke health-related basic BSL skills and Deaf Equality training
- **4.** All NHS Trusts to develop systems to ensure that the communication preferences of patients are recorded; listing preferred registered interpreters who are automatically booked when a patient is called for an appointment
- **5.** All GP surgeries to ensure that patient communication preferences are recorded on their systems and booking interpreters is an established routine when a Deaf patient has an appointment. Details are also passed to the hospital or other health services when referral are made
- **6.** All NHS Trusts and GP surgeries to ensure that BSL interpreters booked are registered with National Register of Communication Professionals for Deaf People (NRCPD)
- **7.** The NHS Choices website should increase the percentage of videos with BSL from 1% to at least 15% by end of 2015
- **8.** All CCGs, NHS Trusts and local Healthwatch groups to make concerted efforts to engage with local Deaf communities and consult with them on a regular basis.

⁴ See Appendix 1

^{5 &}quot;Improving Access for British Sign Language Users" was developed as a response to the All Wales Standards for Accessible Communication and Information for People with Sensory Loss. Copies are available from the BDA.

12. Conclusion

It is clear from these interviews that older Deaf people are disadvantaged when accessing local health services. This is supported by the research carried out nationally by SignHealth that led to the "Sick of It" report. According to the report if all GP surgeries and hospitals carried out good practice in dealing with Deaf patients there would be a saving of up to £30 million a year.⁶

The BDA is a member of the "Our Health in Your Hands" campaign and is actively presenting to Deaf groups across the UK. This informs Deaf people of their rights to "reasonable adjustment" according to the Equality Act 2010. As part of the campaign, Deaf people are encouraged to complain. Complaints procedures are likely to be a drain on costs and time. The BDA's preference is for good practice to forestall any complaints.

The BDA also believes that good practice will lead to Deaf patients taking more responsibility for their own condition which invariably leads to reduced costs. This is especially important with the UK's ageing population and we believe that there is no room for complacency. A concerted effort needs to be made to ensure Deaf patients are not disadvantaged as less healthy and less informed people place a greater stress on services. Without early intervention with appropriate communication support, there is a high risk of Deaf people developing medical conditions that are more costly to treat.

The findings of this qualitative survey clearly show that older Deaf people are struggling to survive with limited communication support wherever they live and that because of the lack of in-built recognition of their needs, their lives are at risk.

The British Deaf Association would like to express their gratitude and thanks to the members of England Deaf Darby and Joan (EDDJ) who gave their time and took part in the interviews and the EDDJ organisers for their support, allowing us to visit and carry out the interviews at their annual rally.

Robin Ash and James Mclean

Empowerment & Campaigns Officers
British Deaf Association

12. Bibliography

- Royal Association for Deaf People (RAD)/(sonus); Older Deaf People and Social Care; A Review by Young, A. March 2014
- SignHealth; Sick of it: How the Health Service is failing Deaf people research report. March 2014
- British Deaf Association (BDA) Discussion Paper; Legal Status for BSL and ISL. March 2014
- British Deaf Association (BDA) Access to Work Consultation. February 2014
- Action on Hearing Loss (AOHL) Communication rights for people who are deaf and hard of hearing.
 December 2012
- British Deaf Association (BDA) Response to the Office for Disability Issues (ODI) Draft Initial Report on the UN Convention on the Rights of Persons with Disabilities (UNCRPD) March 2013
- British Deaf Association (BDA) Access to GPs in North Derbyshire, Commissioned by Derbyshire LINk. October 2012
- British Deaf Association (BDA) Response to the Office for Disability Issues (ODI) on the Consultation "Fulfilling Potential". October 2012
- Association of Sign Language Interpreters (ASLI) Health Survey. April 2012.
- Department of Health (2005) Mental Health and Deafness: Towards Equity and Access: Best Practice Guidance. Department of Health. Accessed: http://www.dh.gov.uk/en/ Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4103995
- Fellinger, JI, Holzinger, D., Dobner, U., et al. (2005). Mental distress and quality of life in a deaf population. Social Psychiatry and Psychiatric Epidemiology, 40 (90), 737-742.
- Lezzoni, L.I., O'Day, B.L., Killeen, M., & Harker, H. (2004). Communicating about health care: observations from persons who are Deaf and Hard of Hearing. Annals of Internal Medicine, 140(5), 356-362.
- Pollard, R. Q & Barnett, S. (2009). Health-related vocabulary knowledge among deaf adults.
 Rehabilitation Psychology, 54(2), 182-185.
- SignHealth (2008). Why do you keep missing me? A report into Deaf people's access to primary health care. Sign Health.
- SignHealth (2009). Why are you still missing me? A report following the publication of the GP Patient Survey 2009. Sign Health.
- Dye, M, Kyle, J.with Allsop, L, Denmark C, Drury A and Ladd P. (2000) Deaf people in the community: Demographics of the Deaf community in the UK, Bristol: Deaf Studies Trust.



Appendix I: BDA's BSL Charter

Local authorities and public services across the UK are asked to sign up to the Charter for British Sign Language (BSL) and make five pledges to improve access and rights for Deaf BSL users.

1. ENSURE ACCESS FOR DEAF PEOPLE TO INFORMATION AND SERVICES

Pledge: Deaf people will get the same quality of provision, information and standards and the same right to be consulted as everyone else.

This will make more Deaf people (include those who have problems with written information) aware of services and able to access these independently. It will also ensure compliance with the Equality Act 2010.

2. PROMOTE LEARNING AND HIGH QUALITY TEACHING OF BRITISH SIGN LANGUAGE (BSL)

Pledge: The families of deaf children and Deaf young people and local authority/public service employees will have access to BSL lessons from suitably qualified teachers.

This will improve communication and bonding between parents/carers, children and siblings, reduce Deaf people's isolation and improve relations between Deaf and hearing people.

3. SUPPORT DEAF CHILDREN AND FAMILIES

Pledge: At the point of diagnosis of deafness, health and education providers will offer parents genuinely informed choices, including a bilingual/bicultural approach.

This will increase Deaf people's academic achievement and job opportunities and enhance family life by improving communication between children, parents/carers and siblings.

4. ENSURE STAFF WORKING WITH DEAF PEOPLE CAN COMMUNICATE EFFECTIVELY IN BSL

Pledge: Customer-facing staff will have basic BSL skills. Specialist staff will have higher-level BSL skills so they can deliver good services to Deaf people without needing interpreters.

This will improve customer satisfaction and reduce the need for BSL/English interpreters when providing specialist services for Deaf people.

5. CONSULT WITH THE LOCAL DEAF COMMUNITY ON A REGULAR BASIS

Pledge: Deaf people will have the right to be consulted on services or changes to services that affect them and to have input into consultations alongside other forums and user groups.

This will improve services for Deaf people, empower Deaf people and free them up to contribute more to the local community.

Appendix II: Narratives

The following are additional transcripts – these are not in any order or organised into any categories.

When I attend a GP appointment I usually communicate via written English but recently had an interpreter, which was great as it made things much similar.

There was one time that the hospital booked a different interpreter who did not have a NRCPD card so I refused to use her and asked her to leave.

(Lady – Wigan)

Most interpreters never give us a feedback form when they have done the job – to ask was the service good or bad. They should have this – but they never do. No consistency – this is a problem as the Deaf community need to be empowered to know how to complain. (Gentleman - South Manchester)

Hospitals are aware and mostly book interpreters – sometimes they forget so I refuse to go in and the appointment is moved.

Fed up when they keep moving my appointments. It's not fair on me. When they cancel I feel fed up — waste of my time. I went to see PALS and had to communicate via notes and they agreed with what I said and now it is on my hospital records stating BSL interpreter for all appointments.

(Lady – Croydon)

A&E is a different story – it is very difficult. When I arrive there, there is always a delay – staff are not aware.

It is very frustrating and depressing for me. (Gentleman – Tameside)

My wife died a few years ago – she wasn't taken seriously. The treatment was slow, she had cancer. There was no interpreter at the GPs so I had to try and communicate myself – much too slow.

Regardless of where we live the NHS should look after us better. I saw for myself what it was like at Charing Cross Hospital – they treated us very badly and there was nothing we could do about it. (Gentleman – Lytham St Annes)

In Leeds it is automatic – if you need an interpreter it is there – no need to ask! For foreign language e.g. Indian it is already translated – why is it not the same for Deaf people? (Gentleman – Huddersfield)

Local GPs rarely book interpreters - they give us a bit of an examination and a bit of paper and off we go. We don't really understand what is wrong with us. . Without an interpreter my wife became really ill – with an interpreter she got better!

There is a big hospital in Padstow – but they don't provide interpreters. Luckily for me my husband is hearing and he interprets for me. The hospital is good just no interpreters. I don't know why – they just don't do it.

The doctor will write down the information - sometimes it is difficult to understand about the medication or tablets etc.

(Lady – Alton, Hampshire)

My husband had cancer of the throat and had no interpreters provided – same old story. He had to have lots of treatment and it made me angry. I wanted them to provide interpreter for him and told them off.

I stayed in hospital with him, as it was too far to travel home and back again. For 7 Days I didn't know what was happening. My daughter came – it's a long way for her to come. She could sign for us and explain what was happening and what the doctor was saying – he just said its Cancer.

It is not fair. The hospital asked me why I went everyday – I said he is Deaf I am the only person he can communicate with.

I don't tend to use interpreters at the hospital I use my daughter. I have a voice and I am very good at speaking.

I am very forceful and when they don't provide interpreters for my friend I tell them off. Sometimes I use my mobile phone to spell words when people don't understand me. (Lady – Southampton)

I usually use my daughter but if I didn't want to take her as I didn't want her to know what is wrong with me they say please bring your daughter! It is not her responsibility really – it is a nuisance really. They are too reticent in using interpreters.

My husband had to have a review and an injection linked to the stroke I asked if an interpreter had been booked. We waited and waited, way past our appointment time and all of a sudden the receptionist burst into tears – she hadn't arranged an interpreter properly. That was the first time – the second time he had to have an injection and go into theatre where he would be awake through the procedure. When he was ready to go in I reminded him to make sure the interpreter went in with him, as he could not understand the doctor if his face was covered in a mask. They refused to let the interpreter in and I was very angry.

I was very angry and not happy at all with this. It would not have hurt to let the interpreter in and I was so disappointed as my husband did not know what was happening. The GPs just don't understand how we feel! How do they understand with a mask over the face! (Lady – Romford, Havering)

Some interpreters get the information wrong and the Deaf person does not understand especially those with Learning Difficulties. They need to consider this point also. They need relay interpreters and Deaf nurses.

I have noticed that a lot of Deaf people do not understand the medication they have been given. They take this home and try to understand the labels and read what it says – they misunderstand when it says no alcohol or do not drive, can make you drowsy. I have had to explain to some Deaf people what it says. They say to me OOPS I didn't realise! No one told me! It is down to communication – the words on the labels are too small. If someone has had a stroke or has Ushers how are they supposed to read these labels? They should have large print on the labels to make it easier. Deaf people think they can give their tablets to their friends as they have the same thing. I have to say to them it is not allowed! – They thought it was OK to share! It is so wrong and it is a big problem.

Deaf people are pulled along in trolleys and they are looking forward and porter is behind them talking – how can they understand that? It is a problem.

There has been some research in our area and it found that 42% of Deaf People don't go to the GP/hospital as they think they are alright. They don't have proper medical checks and this need to be advertised. We need a Deaf person to come and explain this to the Deaf community. They need to be aware of the symptoms and how to recognise them before it is too late – horrendous really. This is important to save lives; they also need the appropriate interpreter support too. If they know then they can get early treatment or even prevent it from getting worse.

The NHS is rubbish and they need to look at this – the Government need to look at this. Why do Deaf people have to suffer? How do we contact people in an emergency? If I ring NHS it takes hours and they ask too many questions – it is a waste of time. It is quicker for a hearing person – they get treatment quicker too. A text message service would be much easier. (Gentleman – Islington)

Hospital is much easier as when I get a letter with an appointment they always book the interpreter. The interpreters are good quality interpreters. Only problem really is the GPs – I don't have support for the dentist but I only go once a year and manage using gesture. (Lady – Wigan)

I had to stay in hospital and when the consultant came to visit he brought a laptop, which had the on-line interpreter service. The signing was very robotic and not clear at all; I could not concentrate because I was in pain. Also, there was a lot of student GPs around my bed, which added to the pressure.

I felt stressed about the whole situation and I was very ill so could not sign properly so the online interpreter was not helping at all.

(Gentleman – Surrey)

When I get an appointment they ask do you need an interpreter or are you bringing a family member! My family lives far away from me so I have to write on a piece of paper that I want a BSL interpreter and show the receptionist. She takes this paper around the back and phones (she says) for an interpreter. She returns saying one is booked. So I turn up to my appointment but the interpreter doesn't turn up. That happened over and over. I was talking to a consultant about an operation I was having and we were going round and round in circles, as I didn't understand what was being said!

Feels like they were passing the buck and I was feeling more and more frustrated so I complained to PALS. It's not just Deaf people who need interpreters and it feels like they concentrate on the foreign people not Deaf people.

(Lady – Solihull)

The dentists very rarely book interpreters. I had to attend hospital for an operation but the interpreter did not turn up, but I was unsure if they had even booked one as could not understand what they was saying anyway. I wanted to ask questions about my operation but could not get my point across to them so had to go through the whole experience knowing nothing at all.

I feel that it is unfair because the Asian community are provided translators so why aren't we. (Lady – Tipton)

I had to attend A&E for a knee injury and had to wait 2 hours before a nurse came to me to say that the interpreters was too busy and that they could not find one. I was left on a trolley bed for the 2 hours, during this time I needed the toilet but due to my knee injury was unable to call for assistance as the buzzer was too far away from the bed. I shouted and shouted for a nurse to come, eventually one did come and that was when I was told that an interpreter was not coming. I was admitted to a ward and again waited 2 days before an interpreter arrived. I made a complaint stating my equal rights about communication access and was sent a letter of apology.

I felt annoyed and disgusted about the whole horrendous and awful situation that I had to endure. (Gentleman – Stafford)

The GP knows that I am Deaf and that I will require a BSL interpreter but they never book one. The hospitals are the same; it is a problem when I cannot access information properly about my medical condition. I have an appointment booked for latter on this month for a scan and the consultant has booked an interpreter for then which is a relief.

Relieved when I knew that an interpreter had been booked for my forthcoming hospital appointment but I am worried that the interpreter will not turn up. (Gentleman – Tipton)

I had been booked for an eye operation, arrived at the hospital and waited for the interpreter to arrive but never did. I had to go through the whole procedure without communication support. (Lady – Stafford)

I had an operation on my leg, which meant that I had to stay in hospital to recover. One day the GP came round and told that I was better and that I would be discharged that day. During the whole stay I did not have access to an interpreter so could not, on that time, explain to the consultant that I was in real severe pain with my leg, nor could I fully understand what he had said only that I was being discharged.

I attended a nurse's appointment at the GP but could not understand her at all; the whole appointment was without communication.

I feel disgusted in the health system and that interpreters should be booked. (Gentleman – Folkestone)

I have had an appointment at the hospital where I waited 20 minutes then asked the receptionist where the interpreter is; I was informed that they were not coming. This caused the appointment to be delayed, as they should have informed me on arrival.

It is unfair that if Deaf people arrive later than 30 minutes to the appointment then the interpreter leaves and still gets paid.

Unfair, Angry, Distraught, Horrendous, Blame the interpreter. (Gentleman – Lewisham)

I have had hospital appointments where either the interpreter has not turned up or the health professional communicates via written English, either way I am left with many unanswered questions.

I prefer female interpreters rather than males due to them wanting to be your friend and helping you rather than just giving you the information.

At the hospital I am unsure if they book unqualified signers but I always make sure that the interpreters have a NRCPD badge. (Lady – London)

I had to go to hospital for a blood test but after 30 minutes of waiting was told that there was going to be no interpreter provided. I should have just walked out but could not come back again as I needed to have this test don, we had to communicate using written English, it was so unfair.

(Gentleman – Minehead)

The hospital didn't book an interpreter for me – they asked me a question and because I understood that question and spoke back they said I didn't need an interpreter.

I felt angry about this. They think that Deaf people understand when we don't! I can hear a little but not a full conversation.

(Lady – Cambridge)

The hospital won't allow my daughter to interpret for me at appointments as she is not qualified – they want a qualified interpreter.

The interpreters have no time – it is all down to money and cuts. Interpreters need to stay longer and after the appointment – maybe go for a coffee and explain it again to me so it is clear. (Lady – did not want to disclose area)

At the hospital I had no access and I had to go home. It makes me worried. I need an operation and it makes me think what will happen to me! I am not happy. I had to have a camera down my throat and there was no interpreter present – I ended up with a damaged throat and had to stay in hospital for 9 days. I didn't know what was happening to me. (Gentleman – Worksop)

Previously I had a blood clot – I went to the walk in centre, my first time, and they sent me to hospital. I was worried and I didn't know what to do! There was no interpreter for emergencies. They checked me over and gave me some tablets and told me to come back on Monday for a scan – interpreter was there but low level. I had to decide to either accept this, as I needed the treatment and the risk to my health or not. Finally I accepted 2nd best! I couldn't walk out, as it needed sorting out.

Made me feel stressed! Inside I felt my confidence go down! I can't go back there now – it was a waste of service and they failed me.

(Gentleman – Croydon)

I've have an operation and they did provide interpreters otherwise I would not understand what was happening to me.

Interpreters there made me feel much better as with hearing people they always understand what is being said and to have the interpreter there they tell me what is being said which makes me feel much better.

(Lady - Bedford)

Sometimes when I go to the hospital with my husband and the interpreter is there but then the next time it is a different interpreter. We would like the same interpreter every time but it is not my place to say this to the hospital.

I don't want to hurt the interpreters feelings – cant say to them oh we don't like you or you are not very good and we prefer another one but how do I get my views across. I just don't feel comfortable.

I felt like giving up with the dentist. (Lady – Nottingham)

With support for health it is 'so so' bit hit and miss really. There are no interpreters – I get nothing – no support. The only support I get is from my family who help me. If I have a problem they just don't help. We get no interpreter support, no Social Worker support – it is very poor. (Lady – Coventry)

The problem if everyone uses family and don't ask for interpreters looks like numbers that need it are low.

(Gentleman – Leicester)

Deaf people are struggling – using local interpreters for health is good. There is a lot of misunderstanding of information.

(Gentleman - Solihull)

Amazing, it is really, really good. We always get interpreters provided. I have been very forceful and refuse to accept an appointment without an interpreter, as I just cannot understand.

Support is good for Deaf people in Islington. (Lady – Islington)

For health settings they need a simple system with simple signs for the medication/tablets.

I have only had one appointment where an interpreter had been booked the rest of the time they had said that the interpreter had cancelled or had just not turned up. They offered no apology at all for this.

The GPs know that I am Deaf and that I need an interpreter but I am never provided with one. (Lady – Tipton)

No problems really especially with the dentist as I can communicate using gesture and let them know when I get pain. The GP knows me well and we can communicate by written English. The waiting room has a screen to let me know when it is my turn. (Lady – Wigan)

There are very few interpreters which means that we rarely get one offered at appointments. The GPs are reluctant to pay for this support and say that we can manage via written English. On rare occasions that they have provided an interpreter then someone has been booked who does not hold a NRCPD registration and low level qualification.

I feel like giving up asking for appropriate communication support. (Lady – Grimsby)

Someone had told me that in our area the health authority was booking level 1 and level 2 signers because they are cheaper than registered interpreters. Also that same person said that a few interpreters were claiming that they are qualified and had faked their NRCPD badge. This is horrendous to think that they can get away with it. But there are some interpreters that are genuine and good at their job.

(Lady – Manchester)

We receive a good service in our area, as interpreters are always booked for communication. On one occasion an interpreter was booked whom did not have a NRCPD registration card, I simply refused to use her.

Upset. (Lady – Fleetwood)

In our area the interpreter provision for health appointments is not good. There is an agency that is often used who has 5 interpreters that are booked to cover the health appointments. The problem is that the agency charge £140 per hour which means that the health authority are reluctant to pay for this, therefore we as Deaf people suffer. (Lady – Hampshire)

I think that it is better to educate the Deaf children at school about services and communication access rights. It will be better to ensure that the next generation are well informed about their rights.

(Gentleman – South Wales)

My husband is hearing so he interprets for me in any medical appointments, he also asks the health professional to write down an explanation of the meeting so I can read it when I get home. Therefore I feel that our NHS provision is good in our area. (Lady – Cambridge)

I am Diabetic and have cancer, I have to have regular check ups and for 6 years I had the same interpreter – I normally can ask for the same one. It has changed now – they said if I want the same one I have to book this myself – why? – as they now use an agency and book different interpreters. Also the agency should book local interpreters – it is my body, my life and my choice! It is really bad and much worse now – they used RNID interpreters all the time. (Gentleman – Trafford)

Interpreters don't turn up – at hospital. GP is very good and I get interpreter but the hospital won't provide them. The interpreter service there is very poor.

I feel like they discriminate against me!

I always feel let down; they should bring in proper interpreters. (Gentleman – Manchester)

I can't have a proper talk with the doctor and it is embarrassing – it is a waste of time – I prefer a woman. I told the doctor to book an interpreter but there was no one there. It is the receptionist's responsibility to book and I just didn't understand.

I feel like giving up. I can't explain properly to the doctor and that is my fault! I can't help it. I need an interpreter all the time – why are the interpreters always cut, it makes me depressed. I need the full information that is what I need.

(Lady – did not want to disclose area)

The hospital won't allow my daughter to interpret for me at appointments as she is not qualified – they want a qualified interpreter.

The interpreters have no time – it is all down to money and cuts. Interpreters need to stay longer and after the appointment – maybe go for a coffee and explain it again to me so it is clear. (Lady – did not want to disclose area)

I have a lot of health issues and I am confused really – I am confused about the access – sometimes the access is fine.

(Lady – London)

At the GPs we get no interpreters – the hospital support is lovely. The GPs just don't understand. I asked the doctor for an interpreter and was told they no interpreters! I told them they are wrong – they say no time to sort it out and the doctor does not sign.

I feel I don't understand and I feel unwanted. (Lady – Worksop)

They are not accessible; over and over again they don't provide interpreters. Also if they do the quality is not good. The interpreter told the doctor the wrong information so I got the wrong tablets! I told the doctor this and asked what level the interpreter was... they told me to go away and told me nothing. All I wanted to know was that interpreter qualified!

I feel suspicious because of the previous problems I have had. When I go in I am worried — I don't know which interpreter will be there — I feel like I don't want to do this — everything is last minute with the hospital and the interpreters don't like things to be rushed. I can't communicate properly and don't have a quality conversation with the doctor and I feel things are not translated properly and then the onus is on me to sort it out as well as sorting out my health — I feel I always have to check for clarification.

I feel frustrated, I have lost my confidence. I am exhausted always seem to be fighting for

interpretation – Deaf people need the information about their health conditions.

(Lady – Essex)

(Gentleman – London)

My GP is good, I have good English so am able to communicate with paper and pen but ii know other people need help. When I go to Audiology – they are not Deaf Aware, they talk to me like I am hearing and I am not I am Deaf!

him and it is very stressful for me. I just want them to be aware that Deaf people need the

I have been asked in the past if I can lipread – I didn't understand what was being said. (Person – Leicestershire South)

The British Deaf Association

Vision

Our vision is Deaf people fully participating and contributing as equal and valued citizens in wider society.

Mission

Our Mission is to ensure a world in which the language, culture, community, diversity and heritage of Deaf people in the UK is respected and fully protected, ensuring that Deaf people can participate and contribute as equal and valued citizens in the wider society. This will be achieved through:

- Improving the quality of life by empowering Deaf individuals and groups;
- Enhancing freedom, equality and diversity;
- · Protecting and promoting BSL.

Values

The BDA is a Deaf people's organisation representing a diverse, vibrant and ever-changing community of Deaf people. Our activities, promotions, and partnerships with other organisations aim to empower our community towards full participation and contribution as equal and valued citizens in the wider society. We also aim to act as guardians of BSL.

- **1. Protecting our Deaf culture and Identity** we value Deaf peoples' sense of Deaf culture and identity derived from belonging to a cultural and linguistic group, sharing similar beliefs and experiences with a sense of belonging.
- **2. Asserting our linguistic rights** we value the use of BSL as a human right. As such, BSL must be preserved, protected and promoted because we also value the right of Deaf people to use their first or preferred language.
- **3. Fostering our community** we value Deaf people with diverse perspectives, experiences and abilities. We are committed to equality and the elimination of all forms of discrimination with a special focus on those affecting Deaf people and their language.
- **4. Achieving equality in legal, civil and human rights** we value universal human rights such as the right to receive education and access to information in sign language, and freedom from political restrictions on our opportunities to become full citizens.
- **5. Developing our alliance** we value those who support us and are our allies because they share our vision and mission, and support our BSL community.

Campaigning for Equal Rights for Deaf people

Notes:

To contact the British Deaf Association please look at our website: www.bda.org.uk

Email: bda@bda.org.uk ooVoo: bda.britdeafassoc Skype: bda.britdeafassoc

Company limited by Guarantee No 2881497 Registered Charity No 1031687 Scottish Charity Number SCO42309

© 2014 BDA