

**SICK
OF
IT**

HOW THE HEALTH SERVICE IS FAILING DEAF PEOPLE

**THE DEAF HEALTH
CHARITY
SIGNHEALTH**

CASE STUDY – SANDRA



Sandra suffered post-natal depression for 16 years.

“My son was born in 1994. I became depressed. I kept on crying. I went to my doctor and we communicated using pen and paper.

I got brief information on post natal depression, and tablets. I saw Prozac on the box and it scared me, so I threw them away. He kept prescribing more.

I gave birth again, and the depression was far worse.

There was a new doctor at the surgery. I expected the same old story, but she asked if I’d used an interpreter. I hadn’t.

With an interpreter, I started to express my feelings and got carried away. I was referred for counselling with three-way communication. My feelings and frustrations were still held in my chest. But, when I met a deaf counsellor I felt all my thoughts pouring out, emptying tension from my body.

I feel much more positive now, it’s time to move on. We need more deaf counsellors.”

FOREWORD



This report should be enthusiastically welcomed by the Deaf community and everyone who works in healthcare. It’s the first time we’ve ever had such valuable information on the health of Deaf people. It really is long overdue.

I hope this report makes us all think carefully about what we can each do to end the unfairness and injustice. The research makes it clear that there is a lot to learn, and plenty to do.

The really good news is that the recommendations are simple steps which anyone can take. It just needs the health service to think about the needs of all patients, Deaf as well as hearing.

I’m only here because SignHealth and others are already working to make things better. Their InterpreterNow online service helped to save my life. My full story is on page 7.

Deaf people will help to make it easy. We are the experts in the best way to communicate with deaf people, and we know what needs to be done.

This research shows that as Deaf people we face everyday barriers that the wider community simply wouldn’t put up with. Can you imagine forcing hearing people to walk to their GP’s surgery to book an appointment? Can you imagine them having to explain their problems to a doctor who does not understand English, and who replies in another language?

The government and the NHS are already planning some changes which will benefit Deaf patients, but it’s not enough and it’s too slow. Online booking for appointments is a good example. It will be a huge help, but the deadline for doctors to make it happen has been delayed for years.

As the report points out, easier access is an important starting point, but it is not enough. Everyone involved in health care, from government and commissioners to doctors and nurses, needs to work with organisations such as SignHealth to find other ways to reduce these health inequalities.

Getting services right for Deaf people will be a big step towards making the health service fit for everyone. The changes we’re talking about are important ... and I know that more than most.

Andrew
Deaf Patient

INTRODUCTION

This research reveals a story of unintentional neglect, shortened lives and wasted money.

Our health service is making it difficult for Deaf people to get help, missing potentially life-threatening health conditions, and offering poor treatment when a diagnosis is made. It's unfair and unjust.

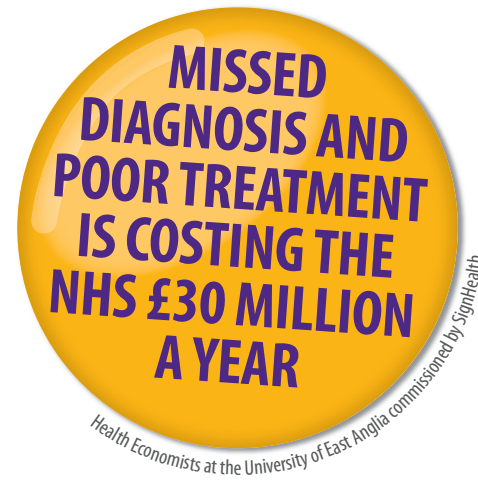
“There is a likelihood of reduced life expectancy in Deaf people.”

Researchers at the University of Bristol in partnership with SignHealth.

Generally speaking, Deaf people are as active as hearing people, eat a similar amount of vegetables, drink less alcohol and smoke far fewer cigarettes.

So, why are they more likely to be overweight, twice as likely to have high blood pressure, and four times as likely to be on the verge of diabetes? Why are so many unknowingly living with health issues which can lead to heart attacks, strokes and other serious conditions?

The answer is lack of information, poor communication, and unnecessary difficulties in getting to the doctor in the first place. All of that is outside the control of Deaf people themselves.



SCAN ME

FOR BSL

Modern healthcare places great importance on giving people information to allow them make healthy choices. Hearing people are bombarded with advice, but we have found a shocking lack of even basic health information in British Sign Language (BSL).

In this internet enabled world of connectivity, 45% of Deaf people still have to walk into their surgery to make an appointment, because of the lack of other ways to do it.

When sign language users finally get to see their doctor, they're forced to communicate in ways that cause misunderstandings, confusion, missed diagnosis and poor treatment. 8 in 10 Deaf people want to use sign language, 3 in 10 are given the chance.

Our health system is failing Deaf people. It's gone on too long and we're Sick Of It. Solutions are simple, affordable and would save up to £30 million a year. We've set them out in our Prescriptions For Change at the end of this report. Please use them.

THE MAKING OF

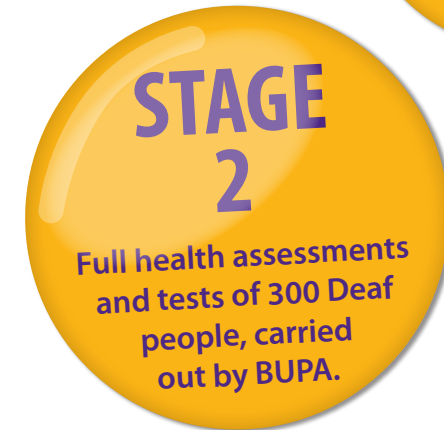
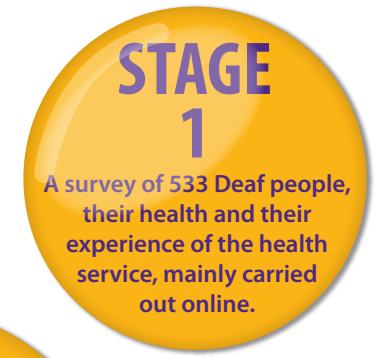
This research is the first big study of its kind anywhere in the world. It's been five years in the making.

Deaf people kept telling us they found it hard to make appointments, that when they got to a consultation they were misunderstood, and that they came away not really knowing what was wrong, or what they needed to do.

So, SignHealth set out to investigate how the service given to Deaf people compares with that given to everyone else. And importantly, whether Deaf people are less healthy as a result.

The research was funded by a grant from the BIG Lottery Fund, and carried out by the University of Bristol.

THE DEAF HEALTH CHARITY SIGNHEALTH



SCAN ME

FOR BSL



POOR DIAGNOSIS

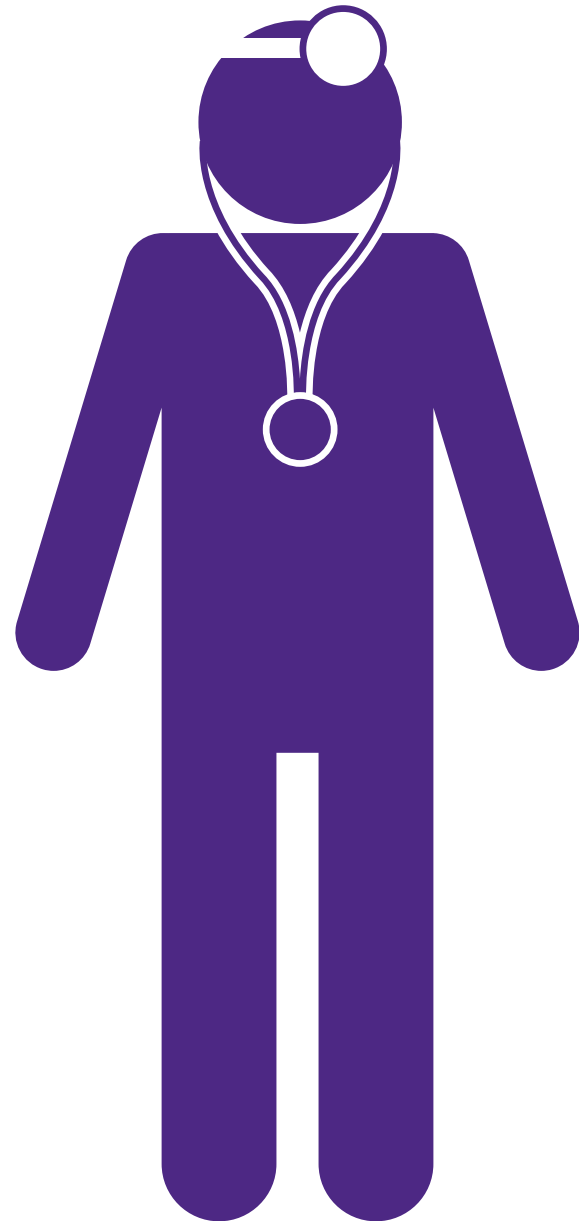
It's much more common for doctors not to spot and diagnose health conditions in Deaf people. That includes problems which can lead to life-threatening illness.

The research results suggest that many of the Deaf people who took part in the study should have been under monitoring or treatment for conditions which they didn't even know they had.

High blood pressure is one of the major causes of heart attacks and strokes. Deaf people are twice as likely as everyone else to have high blood pressure and not know it.

Without diagnosis there is no treatment, and no knowledge that a change in lifestyle may be needed.

Our researchers found that almost one in twelve Deaf people had higher than normal blood sugar levels, a warning sign for diabetes. That's nearly four times the rate of pre-diabetic cases in the rest of the population.



SCAN ME

FOR BSL



“Almost one in twelve Deaf people had higher than normal blood sugar levels, a warning sign for diabetes.”

POOR TREATMENT

Even when Deaf people have been diagnosed, they are less likely than hearing people to be treated properly or effectively. We found this with high blood pressure, heart disease, diabetes and high cholesterol.

Deaf people who've been told they have high blood pressure are three times more likely than everyone else to still not have it under control, 62% of Deaf people compared with 20% generally. They are also less likely to be on medication (only 36% compared with 57% in the wider population).

Where high cholesterol is a problem, Deaf people are far less likely than others to be given treatments to reduce it, such as statins. Less than one in three Deaf people are prescribed a treatment. It's more than two in three for the general population.

More than half of Deaf people with diabetes had inadequate treatment.

Our research shows that many Deaf people are unsure why they are taking their medication. It seems doctors aren't making sure their Deaf patients understand what is wrong, or what their treatment and medication is for.



Giving information clearly in a format that the Deaf patient can understand is one of the important Prescriptions For Change at the end of this report.

DEAF PEOPLE WHO'VE BEEN TOLD THEY HAVE HIGH BLOOD PRESSURE ARE THREE TIMES MORE LIKELY THAN EVERYONE ELSE TO STILL NOT HAVE IT UNDER CONTROL
62% OF DEAF PEOPLE COMPARED WITH 20% GENERALLY

CASE STUDY - ANDREW

"I've had a kidney transplant, a heart attack, and a hernia. In all I've had 11 operations and never got an interpreter.

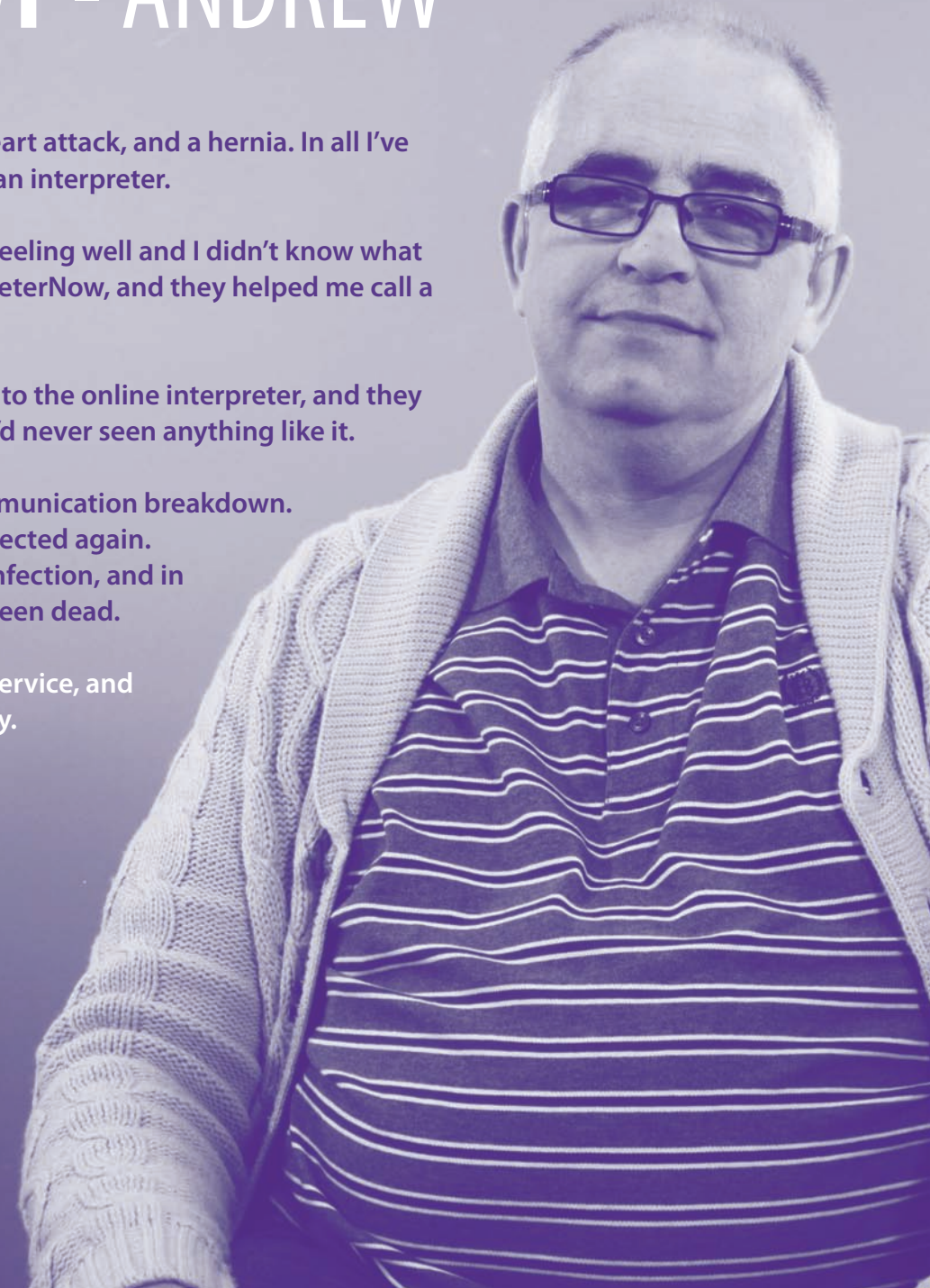
Late one night, last year, I wasn't feeling well and I didn't know what was wrong. I logged-on to InterpreterNow, and they helped me call a doctor.

When the doctor arrived, I signed to the online interpreter, and they spoke to the doctor by phone. He'd never seen anything like it.

Then, at hospital there was a communication breakdown. So, I took out my laptop and connected again. That doctor told me I had a viral infection, and in two or three hours I would have been dead.

I want all Deaf people to use the service, and for it to spread all over the country.

It saved my life."



BAD ACCESS

We couldn't make it harder for a Deaf person to book an appointment if we tried.

In this age of internet and smartphones, 45% of Deaf sign language users can still only make an appointment for themselves by walking into their doctor's surgery. When they get there no-one can use sign language.

Most surgeries make no note of the way Deaf patients would like to communicate. They don't have a simple system to book interpreters which all staff are aware of. That makes every visit a struggle for Deaf patients. It's demoralising, discouraging, and unnecessary.

70% of Deaf people who hadn't been to their GP recently had wanted to go, but didn't, mainly because there was no interpreter.

Difficulties don't end with booking appointments. It's shamefully common for Deaf people to be called from the waiting room by staff shouting their name. Getting access to test results is difficult, as is having them in an accessible form.

Most health professionals seem to be completely unaware that these barriers exist. Audiology departments and Ear, Nose & Throat specialists treat a high number of Deaf patients, so you might expect them to be far more aware and accessible. Shockingly, it's not the case.



Deaf awareness training, and rapid movement towards online and SMS text bookings, are among our Prescriptions For Change at the end of this report.

70%
OF DEAF PEOPLE
WHO HAVEN'T BEEN TO THEIR GP
RECENTLY WANTED TO BUT DIDN'T
GO MAINLY BECAUSE
THERE WAS
NO INTERPRETER

"MY DOCTOR IS GOOD AT LISTENING"

15%

51%

Deaf

Everyone

"THE DOCTOR'S RECEPTIONIST IS NOT HELPFUL"

40%

8%

Deaf

Everyone

COMMUNICATION ISSUES



To understand the confusion and apprehension of a Deaf sign language user visiting the doctor, it's helpful to imagine being in need of medical care while you're on holiday. It's a country where you can make some conversation, but you don't have the vocabulary to make the doctor understand, or to catch the diagnosis and details of treatment.

Our research shows that 8 in 10 Deaf people want to communicate using BSL. Only 3 in 10 get the chance.

That means medical professionals are failing to understand their patients, and their patients don't understand them. The result is poor diagnosis and poor treatment.

The Equality Act means that BSL/English interpreters should be provided, if that's the way the Deaf patient would like to communicate.

ONLY 3% OF DEAF PEOPLE WANT TO COMMUNICATE WITH THEIR DOCTOR BY LIPREADING BUT 40% ARE FORCED TO

Most Deaf patients have little confidence in their doctors. Almost one in five Deaf patients have no confidence in their GP at all, and trust has broken down completely. They are nearly five times more likely than hearing patients to feel that way.



CASE STUDY – ANON

“For three years I was ill, and went back and forth to my doctor. Work were fed up, and I was nearly sacked.

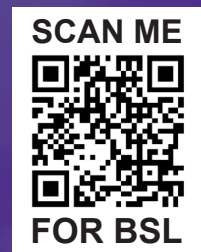
My GP kept saying there was nothing wrong. Then, he said “I think you have depression”, but I knew it wasn't depression.

He referred me to a psychiatrist. I left the surgery feeling a lot more frustrated, which is only natural.

Then one day, when I went to the toilet, I lost three pints of blood. I was admitted to hospital as an emergency, and stayed for five weeks. The specialist told me it was a blood disorder. He thinks I've had it all my life.

What happened is not fair. I've had enough of difficulties and complications in accessing health services.

I'm sick of it.”



NO INFORMATION

In our research Deaf people reported feeling excluded, marginalised and disenfranchised by the healthcare system. They face constant barriers as they try to take control of their own health.

Modern healthcare relies on people being given information and then making healthy choices, but Deaf people are just not being given the information they need.

Health information from the NHS and others should be routinely translated into sign language, to give Deaf people the same access to information as everyone else.

There also needs to be a national programme to make the important information which is already available to hearing people accessible to Deaf people too. It's particularly important that Deaf people can find information when they want it, because unlike hearing people they don't pick up information in passing from the radio and tv, or overheard conversations.

They often need to rely on someone else to translate it for them, such as a friend or family. This would be bad enough for any information, but for something as personal and important as health it is unacceptable.

SCAN ME



FOR BSL

Most hearing people would not be happy with having to ask a friend to explain what an information leaflet says.

Deaf people have poorer access to health services, information and effective communication in consultations.

The in-depth interviews showed that access to health information was poor, with clinicians often relying on written information.

8 IN 10
DEAF PEOPLE
WANT TO COMMUNICATE USING BSL
BUT ONLY 3 IN 10
ARE GIVEN THE CHANCE



“The NHS Choices website contains around 900 videos. Ten of them are in sign language. That’s just over 1%.”

PRESCRIPTIONS FOR CHANGE

It's clear that some simple changes would go a long way towards making the standard of healthcare for Deaf people equivalent to what hearing people are already getting.

The great news is that ending the unfairness and injustice should not require huge investments of money, and some changes will actually make savings for the NHS.

If you are part of the health service, putting yourself in a Deaf person's shoes is a great start. Remembering, and trying to remove the stumbling blocks we mention in this report is another excellent step forward.

Deaf patients have been demoralised by years of neglect and poor treatment. Confidence in the medical profession is low. It needs to be developed with good communication, and new ways of accessing services.

The health economics study which was part of our research showed that poor diagnosis and ineffective treatment of Deaf people are currently costing the NHS £30 million a year. The suffering caused to Deaf people is incalculable.

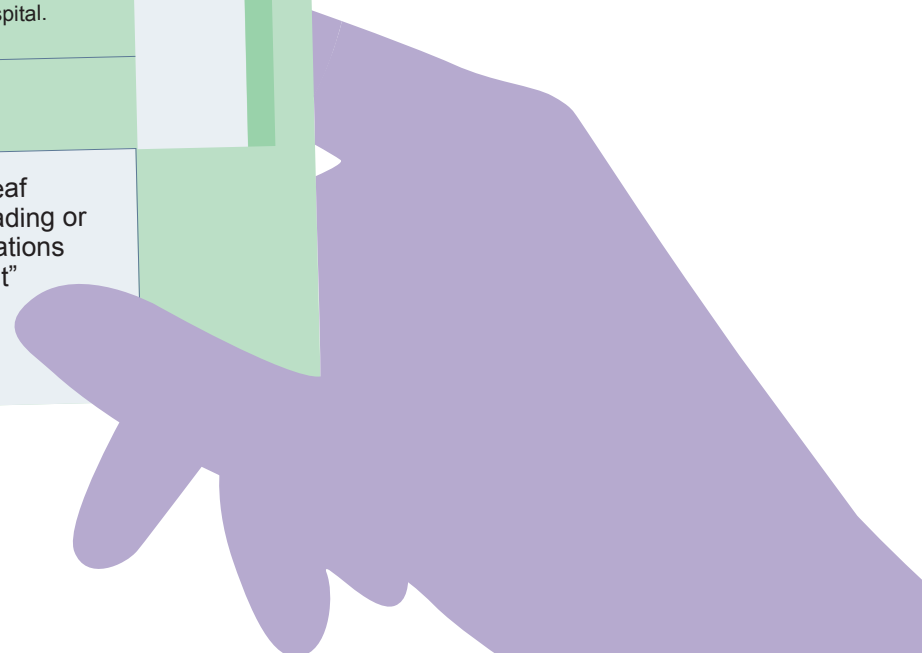
So, what can you do to help make the health service fairer for all? Take away and implement our Prescriptions For Change.



Pharmacy Stamp	Age	Title, Forename, Surname & Address
	D.o.B	
DOCTORS, NURSES AND SUPPORT STAFF		
<small>Please don't stamp over age box</small>		NHS Number:
Number of days' treatment		
<small>N.B. Ensure dose is stated</small>		
Endorsements		
<p>Ask Deaf patients how they would like to communicate with you and record it on their notes so that next time they make an appointment you can make the best arrangements possible.</p> <p>Offer online booking for appointments, and SMS or email contact with the surgery.</p> <p>Book double-length consultations to allow for the interpretation.</p> <p>Make sure you set up a system for calling patients which doesn't rely on them hearing you calling their name.</p> <p>Set-up a simple system for booking interpreters and make sure all staff know how to do it.</p> <p>Take a few minutes to set-up InterpreterNow at your practice for the times when you can't get a face-to-face interpreter quickly enough.</p> <p>NEVER ask a family member to interpret.</p> <p>Check hearing aids are working on admission to hospital.</p>		
Signature of Prescriber		Date
For dispenser No. of Prescns. on form	Remember that unless your Deaf patient requests it, using lip reading or writing things down for consultations is not a "reasonable adjustment" under the Equality Act.	
<small>THE DEAF HEALTH CHARITY SIGNHEALTH</small>		



Go online at www.sick-of-it.com and let us know which of these simple prescriptions for change you will adopt first.



NHS ENGLAND AND GOVERNMENT

Please don't stamp over age box
Number of days' treatment
N.B. Ensure dose is stated
Endorsements

NHS Number:

Routinely collect and record data on whether a person is Deaf, and their preferred method of communication.

Set clear standards for access to healthcare by Deaf people, so that providers and patients are clear about what is expected and acceptable. Have them regulated by the CQC.

Nationally commission specialist services, including sign language based psychological therapies.

Routinely make health information accessible to Deaf people.

Commission more research and engage with the Deaf community.

Signature of Prescriber

Date

For dispenser
No. of
Prescs.
on form

THE DEAF HEALTH
CHARITY
SIGNHEALTH

Pharmacy Stamp

Age

Title, Forename, Surname & Address

D.o.B

COMMISSIONERS AND HEALTH SERVICE MANAGERS

Please don't stamp over age box

Number of days' treatment

N.B. Ensure dose is stated

NHS Number:

Endorsements

Offer Deaf awareness training to all frontline staff.

Ask and record the patients' preferences for communicating during consultations.

Build in the "reasonable adjustments" the Equality Act demands. For sign language users that will usually be access to a sign language interpreter. Communicating in consultations using lipreading, or writing things down, is only a reasonable adjustment if that's what the patient has asked for it.

Test your services on the basis of whether they are accessible to Deaf people.

Collaborate with others to provide economies of scale for services such as interpreting and sign language based psychological therapies.

Pharmacy Stamp

Age

Title, Forename, Surname & Address

D.o.B

DEAF PEOPLE

Please don't stamp over age box

Number of days' treatment

N.B. Ensure dose is stated

NHS Number:

Endorsements

Add your name to the Sick Of It petition at www.sick-of-it.com

Under the Equality Act 2010 doctors and hospitals **HAVE** to do everything reasonable to give you good access. That normally means offering communication support.

Tell your doctor about InterpreterNow. It's not always a substitute for face-to-face interpreters, but it is a great back-up.

Don't just take it. Complain when getting to see the doctor is difficult, and when communication is not good enough.

Follow the Deaf Health Charity SignHealth online for health advice and information in BSL.

IT'S GONE ON TOO LONG AND YOU CAN HELP US CHANGE IT

THE DEAF HEALTH CHARITY SIGNHEALTH

**TIME
FOR
CHANGE**

**THE DEAF HEALTH
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SIGNHEALTH**

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