

# DEAF Wellbeing in NOTTINGHAMSHIRE

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This research was carried out by members of  
the Nottinghamshire Deaf Wellbeing Action Group:  
*Kevin Baker, Gloria Pullen, Les Townend & Robin Ash.*

[nottsdeafwellbeing.org.uk](http://nottsdeafwellbeing.org.uk)  
[nottsdeafwellbeing@gmail.com](mailto:nottsdeafwellbeing@gmail.com)



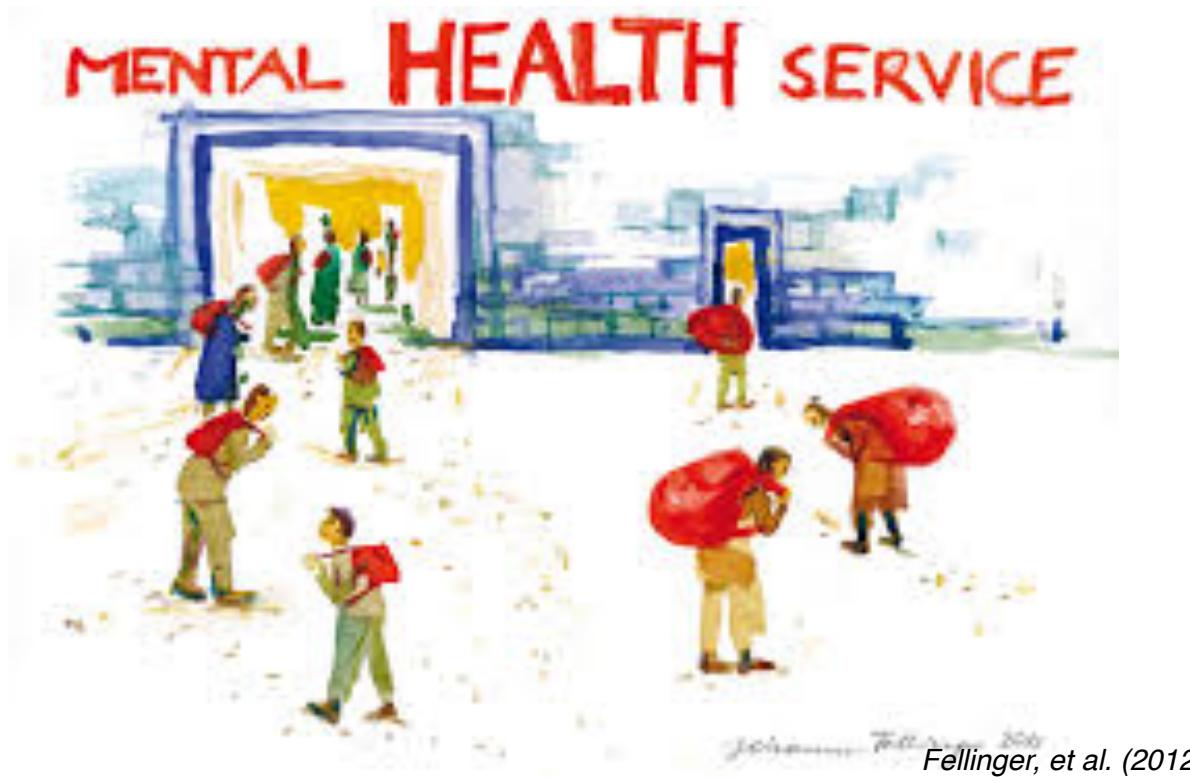
A survey of *Deaf people's experiences of local health services in Nottinghamshire.*

# A survey of deaf people's experiences of local health and social services in Nottinghamshire.

## Introduction

It has been known for some time that D/deaf<sup>1</sup> people experience poorer physical and mental health than hearing people (SignHealth, 2014). Mental Health difficulties occur in around 25% the general population (HSCIC, 2009). However, for Deaf people the incidence is much higher, between 40-50% (Hindley, et al., 1994). There are many factors which affect the lives of Deaf people that can lead to poorer mental and physical health.

A nice analogy about the extra burden Deaf people carry and the difficulties in accessing services is shown in this picture of Deaf people carrying larger loads than hearing people and trying to go through a smaller door than their hearing peers.



In the context of health and social care, Deaf people:

- experience more health problems and significantly poorer quality of life than hearing people (Fellinger et al., 2005, 2012);
- find it difficult to access mainstream physical and mental health care (Perreira & Fortes, 2010; Fellinger, 2012; SignHealth, 2014; Steinberg, et al. 2006);

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<sup>1</sup> In this context, we use the capitalised word “Deaf” to mean culturally deaf people who use sign language as their first language.

- find it difficult to access information about health and social care (Iezzoni, et al., 2004; Pollard, 1998; Steinberg et al., 2006) and consequently have poorer health literacy than the general population (Barnett et al., 2011);
- can find it difficult to understand health information in treatment plans and prescriptions (Reynolds, 2007; Pollard & Barnett, 2009);
- experience poorer health than the general population (SignHealth, 2009, 2014);
- are more likely to visit their GP more frequently than the general population (SignHealth, 2009).

In 2011 we carried out our first survey asking D/deaf people in Nottinghamshire about their experiences of both health and social care services. We wanted to know whether the international research described the same problems that D/deaf people in Nottinghamshire experience. Our findings suggested that this is true.

Between June and November 2014, we carried out a similar survey focusing solely on deaf people's access to health services in Nottinghamshire. This report presents what we found. We also wanted to see if anything had changed in the intervening three years. Unfortunately, we don't think it has.

It is our hope that local services will pay attention to these findings because they know that the research applies to the D/deaf people who live in the areas they serve and use their services.

## **The Deaf Population in the East Midlands and Nottinghamshire**

Estimates about how many D/deaf people live in the UK have always been approximate because of the difficulties of collecting the information and also because of the differences between deaf people. This is important information because services need to know how many people need specific access to information and services so that they can prioritise.

The 2009/2010 GP survey estimates that there are about 7900 deaf people in the East Midlands. Information from the old Primary Care Trusts suggests that there are around 1730 deaf people living in Nottinghamshire. We do not know how many of these people would identify themselves as culturally Deaf or who use sign language as their first language because this information has never been collected. We think that this is important information which should be considered when planning and commissioning physical and mental health services.

## **How we carried out the survey**

We used the same approach as we did with our 2011 survey: We developed a questionnaire to ask Deaf people about their experiences of health services. Everyone involved in developing the questionnaire was a fluent BSL user. We spent time making sure that the questions were clear and that we could explain them clearly to other Deaf people

We know that many Deaf people get put off by forms and writing in complicated English, so we kept the questions simple and clear. We took the forms with us and met with D/deaf people face-to-face and discussed the questions with them to make sure everyone understood what we were asking.

We recorded people's responses to our questions in written English and added anything relevant that they mentioned about their experiences of health services.

We asked about 3 main areas related to health care. These areas were discussed by Deaf people in Nottinghamshire in a focus group as important to them at the moment:

- 1. *Visiting the GP***
- 2. *Feeling depressed, worried and emotional***
- 3. *Going to a hospital appointment***

As with our 2011 survey, we took the questionnaires with us when meeting with the deaf people who agreed to participate in the survey. Our interviewers went to deaf events, contacted friends and family, and travelled to Deaf sports events and Deaf pubs in the Nottinghamshire area to recruit participants.

We managed to ask 43 deaf people about their experiences over the past 12 months. We did not record any identifying information and names were not written down.

Twenty-four of the participants were female, and nineteen were male. Eighteen lived in the City and twenty in the county (five people did not want to tell us where they lived). The average age was 51, (range 19-73, median 53).

The majority (41) said they were BSL users, 2 said that they normally used speech to communicate (oral), even though they can sign.

## What we found out

### 1) Visiting Your Doctor/GP

We asked people about visiting their GP. We know that deaf people experience poorer health, visit the GP more often, and have more difficulties making doctor's appointments than hearing people (Sign Health, 2008, 2009, 2014).

Most people (26, 60%) said their GP was helpful. About a quarter (11, 26%) said that their GP was not helpful.

These numbers are not much different from what we found when we asked the same question in 2011.

When we asked people about how they made an appointment with their GP, 60% (26) told us that they usually make appointments through an interpreter (14, 33%) or family member (12, 28%) using the phone. Some people (4, 9%) used text/fax/online. About a quarter of people (11, 26%) said they have to visit the GP surgery in person to make an appointment.

In 2011, we found much the same: most people asked a friend, a relative or an interpreter to call on the phone (49%); and 30% of them had to visit the surgery in person to make their appointment.

### What we think:

*No Deaf person should have to visit their GP in person to make an appointment.  
Hearing people don't have to do this.*

About half of the sample (22, 51%) said that they always take someone with them when they visit their GP. Many people told us that this was to help them understand what the GP was saying. However, nineteen people (44%) said that they prefer to go on their own. We think this may be because they want to keep the appointment confidential.

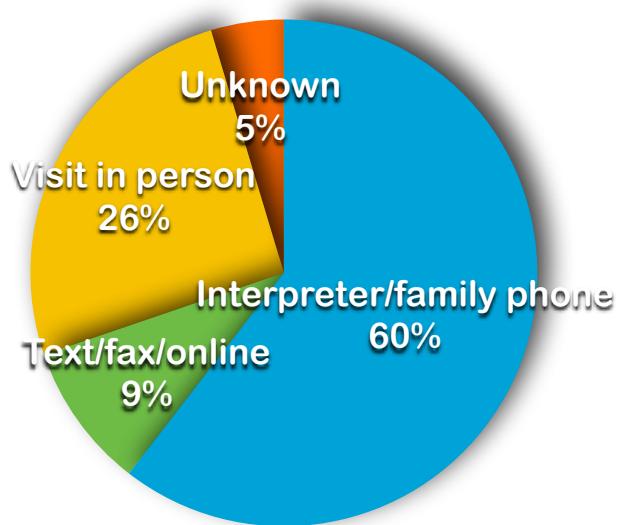


Figure 1: Responses to the question: "How do you make an appointment to see your GP". (N=43).

A few people described the difficulties they experience when visiting their GP:

“I don't understand what the doctor says, but my daughter tells me and explains when we go home”

“I wish the surgery had a message screen when they call patients. The doctor called out my name but he stands around the corner, so I am not sure if my name is called. I always have to get up and ask.”

We asked people about how they communicated with their GP during their appointment. The people who usually made their appointments with an interpreter also usually visit their GP with an interpreter (14, 33%). Other people used methods which we know can be problematic, such as, relying on family members (8, 19%), writing things down (11, 26%), and lip-reading (10, 23%). Two people (5%) said that they use gesture and some signing, even though none of the GPs in Nottinghamshire are fluent in sign language.

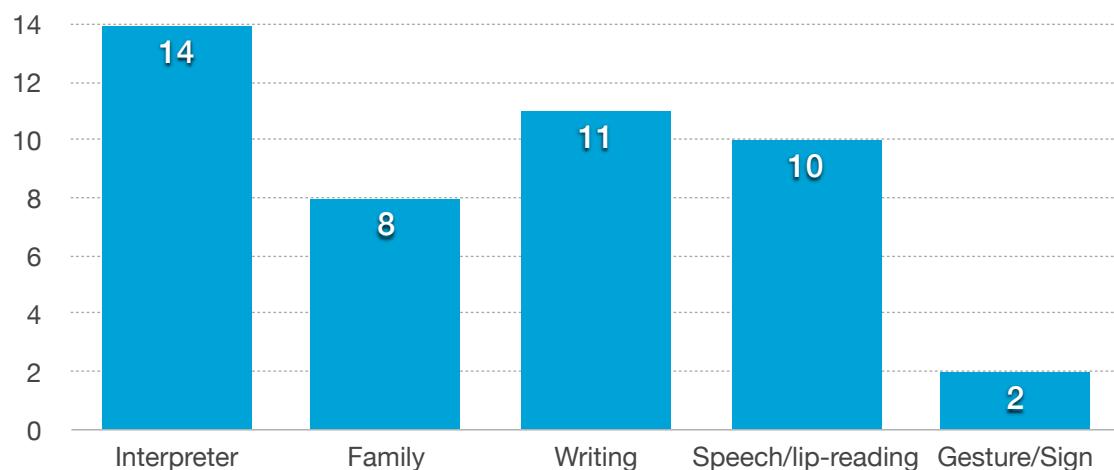


Figure 2: Responses to the question: “How do you communicate with your GP?” (N=43)

We are quite concerned about this finding because we know that many problems can arise through communicating without a qualified sign language interpreter. This is important because it has been found that Deaf people can often find it difficult to understand and remember written information (Holt, 1993) and can find health information confusing (Barnett, et al., 2011).

However, most people (34, 79%) said that they understood the treatment their GP gave them. We cannot be sure about this because we did not ask more questions about their treatment. We also know that many Deaf people do not want to appear as if they don't understand and can often agree with hearing people.

About a fifth of the people we talked to (8, 19%) admitted that they did not understand the treatment that their GP had given them. We do know from the international research literature that many Deaf people report not fully understanding instructions from their doctors (Iezzoni et al., 2004).

### **What we think:**

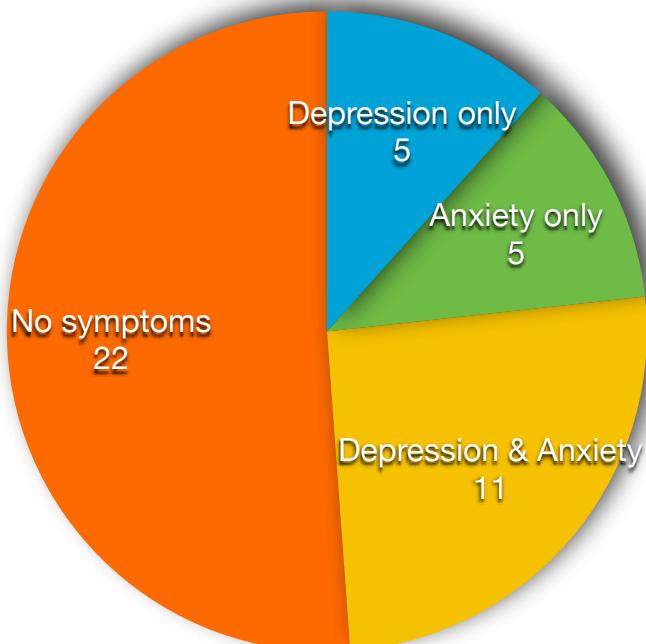
*Every person who visits their GP should leave with a good understanding about their treatment.*

*Deaf people need better access to information about health and health services*

### **2) Feeling depressed, worried and emotional**

We know that the incidence of common mental health problems in the Deaf community is higher than in the general population (Hindley, et al., 1994; Fellinger, et al., 2012). We also know that many Deaf people may not fully understand the clinical terms of "depression" and "anxiety" either in spoken or sign language (Sheppard & Badger, 2010). When we asked people about their emotional distress, we made sure that we explained what the main symptoms of depression and anxiety are before collecting their responses.

We asked people if they had experienced symptoms of depression and/or anxiety for more than 7 days. About half of the people (22, 51%) told us that they had not felt depressed or anxious in the past year. Just under half of the sample (21, 50%) told us that they had been depressed and/or anxious in the last 12 months. Of these, 5 people had felt depressed but not anxious, and the same number had felt anxious but not depressed. Eleven people had experienced the symptoms of



*Figure 3: Number of people who had experienced symptoms of depression and/or anxiety for more than 7 days in the past 12 months.*

both depression and anxiety. In 2011, 60% of the people we asked had felt depressed or anxious in the past year.

This finding reflects recent research which reports that the incidence of common mental health problems in the Deaf population is around 40%, almost twice that of the general, hearing population (Hindley, et al., 1994).

We asked people where they got help for any mental health problems in the past year. The majority of people (81%, 36) said that they had seen their GP. Five people (12%) told us that they had seen a counsellor who used BSL in the past year. No one said that they had seen a hearing counsellor with an interpreter.

Eighteen people (42%) knew about the Specialist Community Psychiatric Nurse (CPN) service for Deaf people in Nottingham. Of these, eight (19%) said that they would ask them for help, but most (18, 42%) said that they would not.

We did not ask people why they would not ask for help from the specialist CPNs. There may be several reasons for this: it may be because they do not have serious mental health problems needing a psychiatric nurse or secondary care; they may prefer to see a BSL counsellor; or they may not understand the services provided or how to access them.

Some people gave us some explanations themselves even though we did not ask:

“I don’t need a CPN - I just need some Step 2 support or some counselling”

“I mostly talk to my daughters or friends if I have problems”

We asked people whether they knew about the Improving Access to Psychological Therapies’ (IAPT) service called *Let’s Talk Wellbeing*. These are mainstream services for the general population and provide interpreters. Only 9 people (21%) said that they had heard about the IAPT service. This is important to note because we know that the incidence of common mental health problems in the Deaf community is more than the incidence in the hearing community.

Some people told us that they had accessed the *BSL Healthy Minds* IAPT service which is delivered in BSL by a Deaf Psychological Wellbeing Practitioner employed by the Sign Health charity.

“I found Step 2 useful and she told me more about other services”

## **What we think**

*Deaf people should have better access to psychological therapies in their own language at all steps of the stepped care model.*

*Deaf people should have equal access to services across the range in the same way that hearing people do.*

### **3) Getting a hospital appointment**

About half of the people (21, 49%) we surveyed said that they had had a hospital appointment in the past 12 months. We think this is a high number compared to the general population. About half of these people (11, 26%) said that their appointment had gone smoothly. Unfortunately the other people (9, 21%) said that it had been a very difficult experience for them.

Here are some examples of what people told us about their hospital appointments:

“I got an appointment letter from the hospital, but I don’t fully understand what it said. It said that I have to phone for an appointment, but I can’t because I am deaf; and I can’t even go to the hospital to make the appointment in person because I don’t know where to go!”

“There was no interpreter at the hospital because of a full booking. My daughter had to sign for me, which was not ideal. I wished an interpreter was available.”

“I don’t understand appointment letters, but my daughter explains them to me”

We were pleased to find out that not everybody had a bad experience:

“It was easy because an interpreter was booked and communication was good”

## **What we think**

*Hospital appointments for Deaf people should improve so that less people experience difficulties.*

## Feeding back to the Deaf community

We held a feedback event at Nottinghamshire Deaf Society in February 2016 to discuss the results of the survey. Over 25 people attended this event and we discussed the issues that came up from the research.

Everyone identified with the difficulties that the research showed that Deaf people experience when they want help from Health services and hospitals. Many people told us stories about what they had gone through.

These were the main topics that were discussed:

- *Making complaints to health services is difficult for Deaf people. The process seems to be set up for hearing people using telephones or email.*
- *Some Deaf people try to cope with appointments without an interpreter because they want things to run smoothly and deal with the health professional directly. However, this often causes more problems than it solves.*
- *Deaf people wonder why they always seem to be sent to specialist Deaf services, like the CPN Mental Health service for Deaf people. It seems unfair that hearing people get a wide choice of services which Deaf people don't have access to, such as Step 2 Psychological Wellbeing Practitioners and Step 4 Psychology.*
- *Many Deaf people said that they are unsure what services are available to them. They also discussed how they could find out more, and want to be able to make decisions about what is best, but they continuously struggle to find out information to help them make those decisions.*
- *Some Deaf people say that it is difficult to build trust with health professionals. This may be because many health professionals don't know how to help develop a Deaf person's trust in them. Perhaps more awareness about the experiences of Deaf people will help them?*

## What we will do next?

We will distribute this report to Health services and organisations in Nottinghamshire who have an interest in supporting the Deaf community. We will also consult more within the Deaf community to help them develop their understanding and confidence in engaging with the health services and organisations in Nottingham.

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## Appendix: The Questionnaire

### 1. Visiting your Doctor/GP

	Yes	No
When you have any worries about your health or are not well, do you always see your Doctor?	40	2
If yes, are they helpful?	26	11
If no, who else helps you?	-	-
How do you and Doctor communicate?	-	-
How often have you seen a Doctor in the last 12 months?	Average = 5.47 Median = 4 Range = 0 - 26	
How do you make an Appointment to see your Doctor?	-	-
Do you take someone for support when visiting your Doctor?	22	19
Have you ever used an Interpreter when visiting a Doctor or Health Professional?	28	14
Did you understand the treatment or medication Doctor gave you?	34	8

### 2. Feeling depressed, worried, and emotional

	Yes	No
Have you felt <u>depressed</u> in the past 12 months? <i>(Depressed means:- feeling very sad, not interested in anything, not sleeping or eating well, for more than 7 days)</i>	16	26
Have you ever felt <u>anxious</u> in the past 12 months? <i>(Anxious means:- feeling very worried about something, can't stop worrying, can't do normal things because of worry, for more than a few days)</i>	16	27
Do you know where to go for support or to talk to someone when you feel depressed or anxious?	30	11
If yes, have you used any of the following in the past 12 months:		
Doctor	30	3
Social Worker	8	25
Health Professional	17	18
Counsellor	5	28
Phone a Helpline	0	32
Personal Assistant	5	28
Advocacy	1	31
Other	5	25

### **3. NHS services - emotional problems**

	Yes	No
Have you been to see a counsellor in the past 12 months?	5	38
If yes, was this with interpreter or counsellor used BSL?		
with interpreter -	0	
BSL counsellor -	3	
Do you know the CPN nurses for deaf people?	18	25
If yes, would you ask them for help?	8	18
Any other comments?	-	-
Have you heard of the service 'Lets Talk-Wellbeing' or 'Health in Mind', where you can receive support and counselling if needed?	9	33

## **4. NHS services - Physical Healthcare**

	Yes	No
In the past 12 months, have you had a Hospital appointment?	21	20
If yes, was this:		
difficult,	9	
or easy, smooth?	11	
Any other comments?	-	-

## **5. About you**

**Gender:**

Male 19  
Female 24

**Age:**

How old are you?  
Average 51  
Median 53  
Range 19 - 73

## **Employment:**

Working	19
Unemployed	9
Student	-
Retired	14
Other	1

## **Do you live in Nottingham City or in the County?**

18  
20

## Deafness and Communication?

Profoundly Deaf	36
Partially Deaf	5
Hard of Hearing	1
Deafened	-
Deaf/Blind	-
BSL	34
SSE	1
Oral/Lipreading	4

## Ethnicity

White British 40  
Black British/Caribbean 3