DEAF WELLBEING IN NOTTINGHAMSHIRE



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A survey of Deaf people's experiences of local health and social support

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Recent research suggests that Deaf people experience poorer physical and mental health than hearing people, and that Deaf people find it difficult to access services. Local services need to be aware of their local communities in order to provide and plan services. We designed a survey to find out about local Deaf people's experiences of health and social care.

We found that although some Deaf people have good experiences of health and social services, a lot of Deaf people experience difficulties. These difficulties are not new. The problems described in the research literature also apply to Deaf people living in Nottinghamshire.

Deaf Wellbeing in Nottinghamshire

A SURVEY OF DEAF PEOPLE'S EXPERIENCES OF LOCAL HEALTH AND SOCIAL SUPPORT

FOREWORD:

The Deaf Wellbeing Action Group developed from concerns raised during discussions of the Deaf Wellbeing Community of Interest. The Deaf Wellbeing Community of Interest is one of several pilot projects initiated by Nottinghamshire Healthcare NHS Trust, with the aim of bringing people from local communities together to influence how health services are provided. This Community of Interest is sponsored by Professor Mike Cooke, Chief Executive of Nottinghamshire Healthcare NHS Trust and was initiated and led by Emmanuel Chan, Specialist Lead for Adult Mental Health Services for Deaf People in Nottinghamshire Healthcare NHS Trust.

INTRODUCTION

Some years ago, at a Hospital in Austria, researchers compared the physical health of Deaf people with hearing people. They found that Deaf people had more health problems and experienced significantly poorer quality of life than hearing people even though there was no difference in the number and quality of social relationships (Fellinger et al. 2005).

In the UK, the charity SignHealth helped the national GP survey collect information about Deaf people (SignHealth, 2008, 2009). From this survey we have a good idea about Deaf people's physical health problems in the UK. The findings are similar to the earlier study in Austria.

In the GP Survey (2009), the percentage of the Deaf Community who said that their health is 'Poor' was 10% compared to 6% of the national population. And 30% of Deaf people who thought that they needed to see their GP weren't able to, compared to 11% of the general population. Many studies have shown that Deaf people find it difficult to access mainstream physical and mental health care (Fellinger et al., 2005; Pollard & Barnett, 2005; Iezzoni, O'Day, Killeen & Harker, 2004).

It is very difficult to estimate the level and frequency of mental health problems in the Deaf population. Mental Health is a complex subject and it is very difficult to measure. We know that many hearing health professionals find it difficult to carry out good assessments with Deaf people around their mental health (Glickman & Gulati, 2003). For these reasons, we may expect Deaf people to experience more frequent and worse mental health than hearing people.

Note:

In this report we use the convention of capitalised "Deaf" to refer to people who identify themselves as culturally Deaf and use sign language as their first language. Where we have used the word "deaf", we are referring to all people who cannot hear. Not all deaf people identify themselves as culturally Deaf.

NOTTINGHAMSHIRE

There has been some research about Deaf people and their health in the UK and other countries. We wanted to know more about local Deaf people in Nottinghamshire and what they thought about their GP and their social services.

It is difficult to guess how many Deaf people there are in Nottinghamshire. Until very recently, each area had a Primary Care Trust which has some responsibility to buy the NHS health services on behalf of their local population. When planning and providing services, it is important for each PCT to know how many deaf people live in their area. In the East Midlands there are about 7900 deaf people (GP Survey 2009/10). The PCTs in our region have made estimates of the numbers of deaf people in each PCT area:

Primary Care Trust	Deaf Adults per 1000 population	Number of Deaf Adults
BASSETLAW PCT	1.3	108
DERBYSHIRE COUNTY PCT	1.6	851
DERBY CITY PCT	5.1	857
LEICESTERSHIRE COUNTY & RUTLAND PCT	1.4	700
LEICESTER CITY PCT	5.7	1,196
LINCOLNSHIRE PCT	1.9	958
NORTHAMPTONSHIRE PCT	3.4	1,616
NOTTINGHAM CITY PCT	3.6	757
NOTTINGHAMSHIRE COUNTY TEACHING PCT	1.8	862

We do not know how these estimates have been made, and whether this includes all deaf people and not just Deaf people who use sign language as their main way of communicating. This distinction is important because we know that the needs of Deaf people are quite specific and not shared by all deaf people. People who have lost their hearing during late childhood or later, and can speak and read English, are more able to access information about their health through books, leaflets and the internet. Deaf people who use sign language as their first language often struggle with written information.

If there are about 7900 deaf people in the East Midlands, with about 1700 deaf people in Nottinghamshire (Nottingham City, County and Bassetlaw), this is a large number who may be experiencing difficulties with their health and social care services. We do not know how many of these deaf people identify themselves as culturally Deaf. We think this is an important distinction that should be considered in planning and commissioning both physical and mental health services.

In this research, we wanted to make a start by finding out more about what local Deaf people think.

WHO ARE WE?

We are a group of people who are interested in improving health and social care for Deaf people in Nottinghamshire. The people who helped design the questionnaire we used and were involved in the interviews were:

Lisa Warnock is Deaf. She used to be a Health Project Worker in the NHS and is now working independently. She also has experience as a user of counseling.

Howard Swinbourne is Deaf and a father of three Deaf children. He is a carer and a campaigner for improving services to Deaf people.

Louise Dexter is a Deaf artist with an interest in working therapeutically with Deaf people with mental health problems.

Anne Darby is Deaf and an independent consultant on Deaf matters.

Kevin Baker is a hearing clinical psychologist who works in the NHS. He has been around Deaf people since he was a child.

HOW WE DID IT

The Questionnaire

We developed a questionnaire to ask Deaf people about their experiences of health and social care services. Questionnaires can sometimes be difficult to design. We spent a lot of time thinking about the questions we wanted to ask. We know that many Deaf people get put off by forms and writing in complicated English. We also spent some time thinking about the words used in the questionnaire and how we could collect as many answers from Deaf people as we could.

The questionnaire was made up of six sections:

- Visiting your GP
- Getting Help from Social Care
- Mental Health and Support Experiences
- Contact with Mental Health Services
- Access to Information
- About you

How we collected information

We decided that it would be most helpful if some of us asked the questions in face-to-face meetings with local Deaf people. Only the Deaf members of our group went out to talk to other Deaf people. We could then explain all the questions in more detail using the Deaf person's preferred method of communication. We could also provide more information straight away if the Deaf person wanted.

We told everyone that the questionnaire was anonymous and we did not record any identifiable information about the Deaf people we talked to. Before we started the project, we talked about and planned for any difficulties that might occur, such as a person asking for help with a problem.

We did not want to simply post out questionnaires and hope for Deaf people to respond. We asked as many Deaf people we could find to complete the questionnaire with us.

WHAT WE FOUND OUT

We collected information from 54 deaf people living in Nottingham city and around the county of Nottinghamshire. Not everybody answered every question, but most people were happy to give us a lot of information.

We have put all the answers to the yes/no questions in the Appendix at the end of this report.

Here is some information about the Deaf people who gave us information:

- 18 (34%) lived in the city and 31 (58%) lived in the county.
- 23 (43%) were men and 27 (51%) were women.
- The average age was 55, and ranged from 18 to 84..

We know that Deaf people from an ethnic minority experience more difficulties than white Deaf people. The majority of people who took part in our survey were white (49, 92%). Two (4%) people said they were British-Black-Carribean. (Two people did not give their ethnic group.)

Most people answering our survey told us that they were profoundly deaf and used BSL as their first language:

- 37 (70%) described themselves as Profoundly Deaf
- 8 (15%) described themselves as Partially Deaf
- 4 (8%) Hard of Hearing
- 1 (2%) Deafened

Most people used BSL as their first language. Most people used more than one form of communication:

- 36 (68%) people said that they used BSL. 22 (42%) people said that they used BSL as their only method of communication.
- 24 (45%) said they relied on speech and lipreading (oral methods). 10 (19%) said that they only use oral methods to communicate (they did not use signing).
- 12 (23%) said they used Sign Supported English (SSE). People who used SSE also used either BSL and oral methods (or both). No one used SSE solely as their method of communication.

1. Visiting your GP

Most of the Deaf people we met told us that they went to see their GP if they had a worry about their health. Just over half (29, 55%) found their GP helpful. A few people did not find their GP helpful (6, 11%) and some said that their GP was helpful sometimes (7, 13%).

Many Deaf people had seen their GP several times in the past year. The average for the group was 5 times. One person had visited their GP about 20 times, and a few people had not seen their GP in the past year.

What people said about visiting their GP

As might be expected some Deaf people have had bad experiences with their GP. But some have had good experiences too. Of those Deaf people who answered this question with an example of their experiences, 25 reported bad experiences and only 3 people reported good experiences and were happy with their GP.

Here is a selection of some of the interesting things people said:

> *"One of my doctors mumbles whilst at computer, I ask SLI* [sign language interpreter] *what he say, SLI say not important as he talks to himself!"*
>
> *"Problem booking SLI and Dr at same time. I ask for clarification using SLI to ask questions to avoid mistakes."*
>
> *"Problem is different doctor every time in A&E so need interpreter. Reception call out is the problem as nurses are either busy or forget. I am deaf and I miss the appointment time till I realise this."*
>
> *"Instead of being able to go myself I have to take my husband, so some things I cannot ask my Dr about because it would be embarrassing. Some of my independence is lost due to my hearing loss."*
>
> *"Very good it is a good surgery."*
>
> *"When I get hospital appointment, I have to go all the way to hospital and ask for interpreter for appointment. Extreme difficult to get Dr.'s appointment because of communication difficulties. Sometimes I do not bother it's too much to cope with..."*
>
> *"When I was in hospital I had a lot of people around my bed and it was frustrating because they was all talking and I could not follow them then they started treatment on me..."*

Communicating with your GP

Many of the Deaf people we spoke to said that they used many different ways of communicating with their GP. Many people used writing (12, 23%). Some relied on talking and lipreading (18, 34%), and nearly the same number said that they use a sign language interpreter (19, 36%). However, many of those who use an interpreter mentioned difficulties with booking and availability.

One Deaf person said they were lucky as their GP came from a family with someone Deaf and could sign well. A few Deaf people said that they could not understand their GP as they were difficult to lipread. Some Deaf people relied on other members of their family (6, 11%).

Making an appointment with your GP

Deaf people try many different ways of trying to get an appointment. Hearing people usually pick up the phone themselves and although they may have to wait if the phones are busy, they can usually

make an appointment fairly easily. Deaf people can use minicom, fax, typetalk or ask someone else to phone for them.

Making an appointment	Number (percentage)
Ask family or friend to phone	18 (34%)
Visit the surgery in person	16 (30%)
Ask a sign language interpreter to call	8 (15%)
Write and send a fax to the surgery	7 (13%)
Use the telephone (with amplification)	5 (9%)
Use the Typetalk service	4 (8%)
Use minicom	1 (2%)

We thought it was interesting that about a third of people actually went to the surgery themselves to make an appointment to see their GP. Hearing people very rarely do this.

We also found that almost half (24, 45%) the people we spoke to took someone with them when they visited the GP. Worringly, about a third of the people (15, 28%) said that they did not fully understand the treatment that they had been prescribed by their GP.

2. Getting Help from Social Care

We asked people if they have someone near them who they can go to for help. Just over half said yes they did (28, 53%), and 42% (22) said that they did not have any family or a carer nearby.

We also asked if people were aware of the social care teams who work with Deaf people. There is a team in Nottingham City (based at the Mary Potter Centre) and a team in Mansfield (based at Meadow House) who cover the county of Nottinghamshire. About half of the people we spoke to were aware of these services. The majority of people knew the service in their area, but did not know the other service.

Of those people who had used the social care services, more people had found them helpful than unhelpful. A few people (4, 8%) told us that they had experienced problems getting an appointment, and others (2, 4%) said that communication was difficult with signing not being good enough for them to feel confident.

3. Mental Health and Support Experiences

We asked people whether they had experienced clinical levels of depression and anxiety, and also what they had done about it. The 60% (32) said that they had felt depressed or anxious at some point in the past. Half (27, 51%) of these people know where they can get some help, but 19 (36%) said that they would not know where they could get help.

We asked those people who had experienced depression and anxiety who they had talked to for help:

Who did you talk to?	Number (percentage)
Doctor	31 (58%)
Counsellor	16 (30%)
Social Worker	9 (17%)
Personal Assistant	5 (9%)
Advocacy	4 (8%)

Even though most people talked to their GP when they were depressed and anxious, we wonder whether they really got any help given that making an appointment with their GP and understanding what he/she says is often difficult for many Deaf people.

The people we talked to often gave us extra information about where they got help. Some said that they try to be positive. Others said that they talk to family and friends, or to people at the Deaf club.

4. Contact with Mental Health Services

We asked people questions about whether they knew about local mental health services. We wanted to know if they were aware of the two Community Psychiatric Nurses who work with Deaf people, and also if they knew about the new Improving Access to Psychological Therapy services (called 'Lets Talk Wellbeing' and 'Health in Mind').

About half of the people we talked to had previously seen a counsellor or a mental health professional, like a nurse (26, 49%).

Just over half knew about the mental health nurses for Deaf people (28, 53%).

Most people (43, 81%) did not know about the mental health drop-in service at the Mary Potter Centre (Nottingham City), but nearly half said that they would use if they needed (23, 43%).

Again, most people said that they did not know anything about the mental health services, Let's Talk Wellbeing and Health in Mind (39, 74%). But more than half said that they would use it if they needed (33, 62%).

5. Access to Information

We asked everyone where they usually got information about their health concerns.

Interestingly, the same number of people who said that they got information from Doctors, Nurses and Health Professionals also said that they get health information and advice from families and friends.

We were not surprised about this, as we expected that Deaf people would get information from people with whom they communicate more easily, such as their family and friends.

Where do you get information/advice about health?	Number (percentage)
Doctor/Nurse/Health Professional	33 (62%)
Family & friends	33 (62%)
Internet/Books/Magazines	22 (42%)
DVDs & television	5 (9%)

We were surprised that not many people used DVDs and television to get their health information.

Many people told us they got information about their health from other people and places, such as support workers, Deaf club friends and staff, and from booklets.

WHAT PEOPLE TOLD US:

Some people gave us more detail about their experiences with health and social care services. Here is a selection:

"Went to hospital for check on my leg - SLI did not turn up. Waited and no-one called me till I was the only one in the end. Went to PALS to complain to them and also to hospital. Went to hospital second time – sent me to QMC for emergency operation on my leg. Think if the appointment was delayed much longer my leg would have been in a serious condition."

"I had a letter from hospital marked "urgent" asking me to ring them. I had no one to help me make the call so I went to my GP surgery and asked the receptionist to ring for me. She refused. I offered to pay her £5 for her to make the call. She refused saying she was not allowed."

"My GP practice do not have contact details of interpreter agency on their files despite the visit of health project worker from NDS. I have to give them numbers when I asked them to make arrangement for me!!"

"Sometimes have a bad time with NHS due to communication, confusion, delays due to lack of information."

"Because my husband goes with me I feel ignored and talked over. They talk to my husband because it is quicker and easier but it leaves me feeling deflated and very useless." (This women was crying while said this)

"Very happy with CPN for Deaf people helping."

"I find the NHS very poor when dealing with blind/deaf people. Some are willing to learn though. Access to interpreters promptly would be a real help."

"I try not bother, too much hassle."

"Waiting rooms. Why don't they have a board that shows your name at Drs and Hospitals? An electronic board that flashes your name when Dr or consultant is ready to see you. Have had quite a few delays because of not hearing my name called out. Gets me very cross."

"My GP is good. I do have problems with communication at my Dentist."

CONCLUSION

It is clear that some Deaf people continue to experience difficulties when asking for help. NHS services are encouraged to offer Deaf Awareness training to all their staff. But we think that maybe local services could be more proactive in providing information about themselves to the Deaf community. We know that this may be hard for them, but the difficulties we have highlighted are not new.

One of the recommendations from the *Mental Health and Deafness: Towards Equity and Access* report (DoH, 2005) is that Primary Care Trusts should consider whether there is a GP practice that could develop a special interest in the needs of Deaf people. We think this would be a good idea and may go some way to improving the health and mental health of many local Deaf people. We think that hearing health professionals will need to enhance their practice with specialist knowledge of Deaf people, their culture and their language.

WHAT WE WILL DO NEXT

We will try to find out more information from more Deaf people about their experiences of health and social care services in Nottinghamshire. We will meet with Deaf people to discuss this report and to think about what research we will do next.

We also want to distribute this report to staff and managers in the local NHS and social care services.

REFERENCES

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, J., 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.

Glickman, N & Gulati, S. (2003). *Mental Healthcare of Deaf People: A culturally affirmative approach.* Mahwah, NJ: Lawrence Earlbaum Associates.

Iezzoni, 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.

Sign Health (2008). *Why do you keep missing me? A report into Deaf people's access to primary health care.* Sign Health.

Sign Health (2009). *Why are you still missing me? A report following the publication of the GP Patient Survey 2009*.Sign Health.

APPENDIX: THE QUESTIONNAIRE

Here are all of the YES/NO questions we asked in the questionnaire with the answers people gave.

Visiting your GP	Yes	No	Sometimes
When you have worries about your health or are not well, do you always see your Doctor?	47 (89%)	6 (11%)	
If yes are they helpful?	29 (55%)	6 (11%)	7 (13%)
How often have you seen a Doctor in the last 12 months?	Ave.= 5	Max.= 20	Min.= 0
Do you take someone for support when visiting your Doctor?	26 (49%)	24 (45%)	
Have you ever used an interpreter when visiting your Doctor or Health Professional?	30 (57%)	23 (43%)	
Do you understand the treatment or medication the Doctor gave you?	29 (55%)	15 (28%)	

Getting Help from Social Care			
Do you have family, carer or someone near who supports you?	28 (53%)	22 (42%)	
Do you know about the Service for Deaf People at the Mary Potter Centre, Nottingham City?	19 (36%)	32 (60%)	
If yes, have they been helpful?	8 (15%)	4 (8%)	
Do you know about the Service for Deaf People in Mansfield?	22 (42%)	26 (49%)	
If yes, have they been helpful?	8 (15%)	5 (9%)	

Mental Health Support Experiences			
Have you ever felt depressed?	32 (60%)	20 (38%)	
Have you ever felt anxious?	32 (60%)	19 (36%)	
Do you know where to go for support or to talk to someone when you feel depressed or anxious?	27 (51%)	19 (36%)	
If yes, have you used a Doctor?	31 (58%)	8 (15%)	
If yes, have you used a Social Worker?	9 (17%)	29 (55%)	
If yes, have you used a Counsellor?	16 (30%)	20 (38%)	
If yes, have you used a Personal Assistant?	5 (9%)	31 (58%)	
If yes, have you used Advocacy?	4 (8%)	30 (57%)	

Contact with Mental Health Service

	Yes	No
Have you ever been to see a counselor or other Mental Health Professional?	26 (49%)	25 (47%)
Do you know the local mental health nurses for Deaf People?	28 (53%)	24 (45%)
Are you aware of the Drop-In service at the Mary Potter Centre?	8 (15%)	43 (81%)
Would you use it?	23 (43%)	16 (30%)
Have you heard of the services "Let's Talk Wellbeing" or "Health in Mind" where you can receive support and counseling if needed?	11 (21%)	39 (74%)
Would you use this service if needed?	33 (62%)	6 (11%)

Access to Information and advice about Health worries

Do you get information or advice from a Doctor/Nurse/Health Professional?	33 (62%)	12 (23%)
Do you get information or advice from family or friends?	33 (62%)	13 (25%)
Do you get information from internet, books or magazines?	22 (42%)	23 (43%)
Do you get information from DVDs or Television?	5 (9%)	40 (75%)

Other sources of information: *Support workers, Deaf Club, Booklets, Deaf Groups, Deaf Club Health Workers.*